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College of Medicine and Life Sciences

CLINICAL DECISION MAKING I
INDI #778

MEDICAL ETHICS HANDBOOK
2012-2013

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Medical Ethics Curriculum Summary 2012-13

SESSION	DATE	TIME	TOPIC
Lecture #1	Wed, August 29	1:00-3:00pm	Principles of Bioethics (<i>Edinger, Marco</i>)
Plenary & Small Group Session #1	Wed, Sept 5	1:00-3:00pm	The Patient Experience (<i>Marco, panel</i>)
Plenary & Small Group Session #2	Wed, Sept 12	1:00-3:00pm	Minors: Consent & Confidentiality (<i>Badik</i>)
Lecture #2	Tues, Sept 18	1:00-3:00pm	Patient Autonomy: Perspectives in the Humanities (<i>Marco</i>)
Plenary & Small Group Session #3	Wed, September 19	1:00-3:00pm	Organ Donation (<i>Rees</i>)
Lecture #3	Mon, Sept 24	1:00-3:00pm	End of Life (<i>Edinger</i>)
Plenary & Small Group Session #4	Wed, Sept 26	1:00-3:00pm	End of Life (<i>Baker</i>)
Plenary & Small Group Session #5	Wed, Oct 3	1:00-3:00pm	Stewardship of Healthcare Resources (<i>Marco</i>)
Lecture # 4	Thurs, Oct 4	1:00-3:00pm	Physician-Patient Relationship (<i>Edinger</i>)
Lecture # 5	Tues, Oct 9	1:00-3:00pm	Conflicts of Interest (<i>Edinger</i>)
Plenary & Small Group Session #6	Wed, Oct 10	1:00-3:00pm	Disparities in Healthcare (<i>Hogue</i>)
Lecture #6	Wed, Oct 17	1:00-3:00pm	Ethical Issues of Genetics, Panel Discussion (<i>Marco</i>)
Lecture #7	Thurs, Oct 18	1:00-3:00pm	Ethical Issues of Genetics (<i>Baker</i>)
Lecture #8	Thurs, Oct 18	3:00-5:00pm	The Future of Genetic Testing (<i>Marco</i>) Movie: GATTACA
Exam	Mon, October 22	1:00-3:00pm	All Ethics Content
Ethics Project Due	Thurs, Nov 8	5:00pm	Ethics Project Due
Ethics Showcase	Tues, Nov 27	12:00-1:00pm	Ethics Showcase (<i>Marco</i>)

Medical Ethics Objectives:

1. Define and describe the significance of the major principles of bioethics, including respect for patient autonomy, beneficence, nonmaleficence, and justice.
2. Understand the “ABC” framework for analyzing ethical issues, including:
 - Assessment
 - Bioethical Principles and Values
 - Capacity
 - Decision
 - Evaluation
3. Compare important ethical opinions related to fundamental topics in medical ethics.
4. Formulate a rational approach to clinical ethical dilemmas.
5. Demonstrate the application of a framework for analysis and the principles of bioethics to clinical cases.
6. Integrate bioethical principles into the clinical practice of medicine.

“ABC Framework for Ethical Issues”

A. Assessment: Gather information, communicate with patient and other parties, and assess objectives of interventions

1. Gather information about the case. Obtain information about the background, clinical information, and expected outcomes of various courses of action.
2. Communicate with the patient regarding goals and values, and objectives of medical care in this clinical scenario. Discuss patient preferences.
3. If the patient is unable to communicate, obtain information regarding advance directives, previous conversations, or family opinions regarding patient preferences.
4. Communicate with family and friends regarding their opinions, goals, and values (if the patient consents to this step).
5. Consider the involvement of additional parties, such as pastoral care, social work, or an ethics committee.

B. Bioethical Principles and Values: Identify and prioritize principle of bioethics and values relevant to the case

1. Identify bioethical principles applicable to the case. Principles may include:
 - a) Respect for patient autonomy
 - b) Beneficence
 - c) Nonmaleficence
 - d) Justice
2. Identify values applicable to the case. Values may include such concepts as honesty, integrity, altruism, respect for life, justice, freedom, and others.

C. Capacity: assess capacity of the patient to participate in medical decision making

1. Assess the decisional capacity of the patient.
2. If the patient does not possess decisional capacity, identify any advance directives or other communications of patient wishes
3. If necessary, identify a surrogate decision maker to speak on the patient's behalf. This is often defined by state law, and may include a hierarchy such as spouse, adult children, parents, etc. If no surrogate can be identified, a court appointed surrogate may be named.

D. Decision: Make a timely decision

1. Identify possible courses of action.
2. Weigh positive and negative ramifications of each possible course of action.
3. Select the course of action that best adheres to ethical principles and values of the patient and the physician.
4. Make the decision in a timely fashion to allow for the best possible outcome.

E. Evaluation: assess the outcome and analyze the ramifications of the decision.

1. Review the clinical outcome.
2. Assess the opinions of the patient, family, and health care providers.
3. Analyze in retrospect whether other options may have been preferable.

AUGUST 29

Principles of Bioethics: (Walter Edinger, PhD/Catherine Marco, MD joint presentation)

Objectives:

1. Define and describe the significance of the major principles of bioethics, including respect for patient autonomy, beneficence, nonmaleficence, and justice.
2. Understand a framework for ethical issues, including:
 - Assessment
 - Bioethical Principles and Values
 - Capacity
 - Decision
 - Evaluation
3. Demonstrate the application of the principles of bioethics to clinical cases.
4. Apply a framework for ethical issues to clinical cases.

Required Readings:

“An Approach to Ethical Dilemmas in Patient Care”, in: Lo, Bernard: Resolving Ethical Dilemmas, A Guide for Clinicians, pp. 3-10.

“Overview of Ethical Guidelines”, in: Lo, Bernard: Resolving Ethical Dilemmas, A Guide for Clinicians, pp. 11-17.

Assignment: Individual Paper - Due September 5, 2012 before 5:00pm (2 points):

Application of principles and the ABC framework to a clinical case.

Explain how you would approach the case, what additional information you would need to make a rational decision, and how you would evaluate your decision.

Suggested length is 1-2 pages to be submitted via Blackboard assignment drop box.

For questions contact Nick Bell.

Case:

A 35-year old male presents with shortness of breath and cough. He is known to be HIV positive. On initial evaluation, his vital signs are stable except for mild hypoxia (SaO₂ = 91%). His chest radiograph shows minimal bilateral diffuse infiltrates. As the primary care provider, you suspect *Pneumocystis jiroveci* pneumonia, and are also considering the possibility of *Mycobacterium tuberculosis*, and numerous other diagnostic possibilities. After hearing of your recommendation for additional diagnostic tests, and immediate institution of antibiotic therapy, the patient refuses these interventions. He states that he is too depressed about being HIV positive to consider any tests or interventions, and just wants some cough medicine and sleep medicine. His partner, who accompanied him, is supportive of the recommended tests and medications.

- A. Assessment: What additional information do you need to adequately assess the case scenario?
Discuss the significance of various pieces of additional information, and how this would affect your perspective.
- B. Bioethical Principles and Values: What bioethical principles and values are applicable to this case?
- C. Capacity: Does this patient have appropriate decisional capacity? If not, who is patient's surrogate?
- D. Decision: What courses of action should be considered? What course of action do you recommend?
- E. Evaluation: How would you assess the outcome of the decision?

SEPTEMBER 5

The Patient Experience: Patient Panel and Small Group Discussion *(Dr. Catherine Marco)*

Objectives:

1. Identify barriers to empathy and compassion in the physician-patient relationship.
2. Discuss factors associated with patient vulnerability.
3. Recommend strategies to increase the physician's empathy and compassion.

Required Readings:

"Promoting the Patient's Best Interests", in: Lo, Bernard: *Resolving Ethical Dilemmas, A Guide for Clinicians*, Fourth Edition, pp. 31-39.

The following 2 articles are two different perspectives on the same case:

Guo HH: Fatal 2009 Influenza A (H1N1) Infection, Complicated by Acute Respiratory Distress Syndrome and Pulmonary Interstitial Emphysema. *Radiographics* 2010; 30:327.

Levinson P: Love, Loss, and the H1N1 flu.

Recommended Readings:

"New Doctor", by F.R. Burdett, from *Virtual Mentor* July 2001

"The Role of the Patient in Medicine – A Personal Perspective (James J. Mezhir)

"Controlling Diabetes" by Hoffman RP, from *Virtual Mentor* November 2005.

Assignment: no assignment.

Discussion Questions:

1. Have you ever been a patient? What are the positive and negative aspects of your experience?
2. What are the differences between the two accounts of the H1N1 case?
3. What are some common characteristics of patients?
4. What are some common barriers to empathy and compassion in the physician-patient relationship?
5. Which do you think is more important, technical expertise or compassion?
6. Is it acceptable for a physician to be proficient and skilled, but rude to staff and patients?
7. Numerous studies have demonstrated a loss of compassion through the medical training process. Why does this occur? How can we prevent it?

Best Cases from the AFIP

Fatal 2009 Influenza A (H1N1) Infection, Complicated by Acute Respiratory Distress Syndrome and Pulmonary Interstitial Emphysema¹

EDITOR'S NOTE

The diagnosis, prophylaxis, and treatment of 2009 influenza A (H1N1) represent a major health issue in 2009 and early 2010. Immense effort and expertise have been expended worldwide in attempt to contain this strain of influenza. Dr H. Henry Guo and colleagues present an excellently documented Best Case from the Armed Forces Institute of Pathology that demonstrates the radiologic-pathologic correlation of 2009 influenza A (H1N1) and its complications. They speculate on possible reasons for severe complications in patients with a compromised immune status.

H. Henry Guo, MD, PhD • Robert T. Sweeney, MD • Donald Regula, MD • Ann N. Leung, MD

History

In July 2009, a 56-year-old man with a history of asthma presented to his primary care physician after 3 days of nonproductive cough, fever, and dyspnea. The patient was treated with clarithromycin and pulse-dose prednisone for presumed community-acquired pneumonia and asthma exacerbation. He returned to the clinic 6 days later with worsening symptoms and speaking in one- to two-word phrases.

The patient was admitted to the hospital, and 1 day later, he was transferred to the intensive care unit because of declining respiratory status. Although initial direct fluorescent antibody (DFA) tests for influenza A+B, respiratory syncytial virus, adenovirus, parainfluenza, and metapneumo viruses were negative, the patient was empirically treated with oseltamivir and broad-spectrum antibiotics. However, his oxygen requirements continued to increase; intubation was performed and mechanical ventilation was begun on hospital day 4. Shortly thereafter, bilateral pneumothoraces and subcutaneous emphysema developed. Multiple pleural drains were placed bilaterally in the ensuing days. Persistent air leak from the right-sided chest tubes was noted.

On hospital day 6, computed tomography (CT) of the chest was performed. Results from real-time reverse-transcriptase polymerase chain reaction (RT-PCR) assay of specimens obtained from bronchoalveolar lavage were positive for 2009 influenza A (H1N1) RNA. Because of increasing difficulties with ventilation, CT pulmonary angiography was performed on hospital day 9; the results were negative for embolism. The patient continued to decompensate, eventually requiring multiple vasopressor agents, 100% Fio₂, and inhaled nitric oxide. Hypoxemia worsened, and on hospital day 16, the patient became profoundly bradycardic and then asystolic. Postmortem examination was conducted shortly thereafter, with the consent of family members.

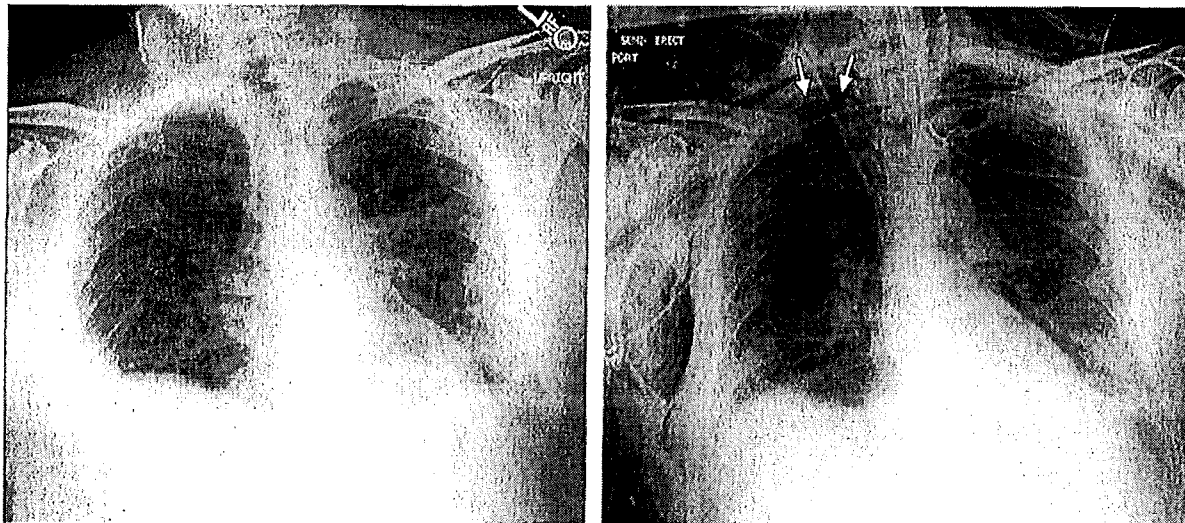
Abbreviations: ARDS = acute respiratory distress syndrome, DFA = direct fluorescent antibody, RT-PCR = reverse-transcriptase polymerase chain reaction

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²RSNA, 2010 • radiographics.rsna.org

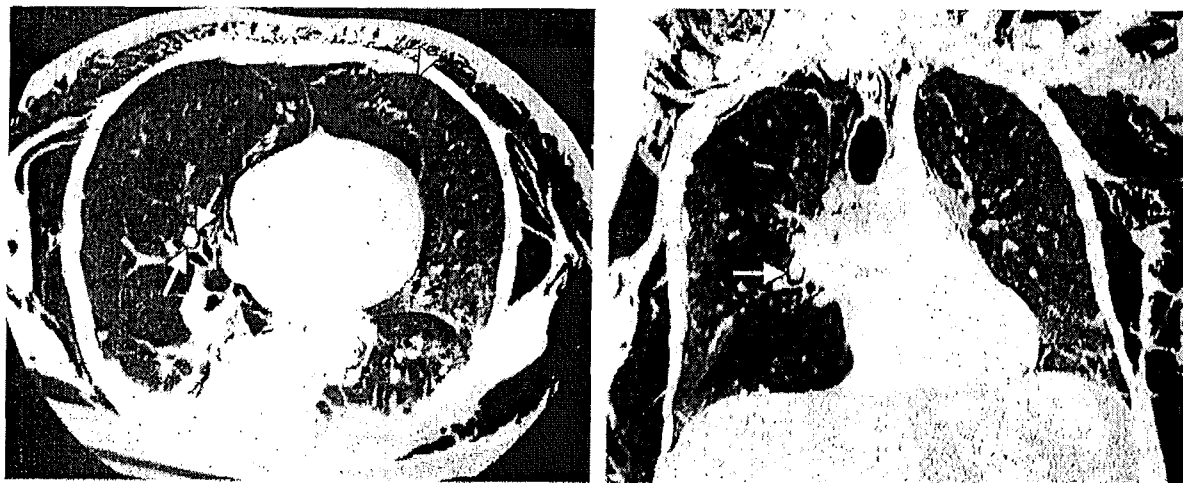
Figure 1. (a) Anteroposterior chest radiograph taken at admission shows low lung volumes with areas of mixed ground-glass and alveolar opacity in a predominantly peripheral and basilar distribution. (b) Anteroposterior chest radiograph obtained 5 days later shows interval intubation and development of pneumomediastinum and subcutaneous emphysema. Diffuse areas of ground-glass opacity persist. Arrows point to a small right-sided pneumothorax.



a.

b.

Figure 2. Axial (a) and coronal (b) CT images (lung window setting) obtained on hospital day 6 show bilateral patchy areas of ground-glass attenuation with dependent areas of consolidation. Pneumomediastinum and bilateral pneumothoraces are seen. A small left pneumothorax is marked by an arrowhead in a. Air surrounds the lobar artery to the right middle lobe, producing a partial “ring-around-the artery” sign (arrows) indicative of pulmonary interstitial emphysema.



a.

b.

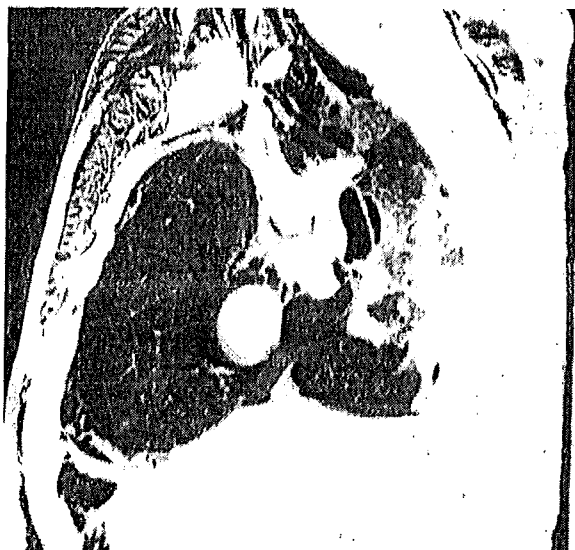
Imaging Findings

Chest radiographs obtained at admission showed low lung volumes and bilateral areas of mixed ground-glass and airspace opacity in a predominantly peripheral and subpleural distribution (Fig 1a). Radiography performed 1 day after intubation, on hospital day 5, demonstrated subcutaneous emphysema, pneumomediastinum, and a small right-sided pneumothorax (Fig 1b).

Nonenhanced CT, performed on hospital day 6, showed diffuse areas of ground-glass opacity with consolidation in a primarily dependent distribution (Figs 2, 3a). Air dissected along the bronchovascular bundle in the right hilum, reflective of pulmonary interstitial emphysema. Extensive subcutaneous emphysema was also present. There was no evidence of pleural effusions or lymphadenopathy.

On hospital day 9, CT pulmonary angiography was performed. No evidence of embolism was present (Fig 3b). However, the lung parenchyma

Figure 3. (a–c) Sagittal CT images obtained on hospital day 6 (a) and hospital day 9 (b) are correlated with a photograph of the gross lung specimen from autopsy (c), obtained shortly after death on hospital day 16. Together, these images show progressive development of cysts that involve the nondependent aspect of the right lung (arrows in b and c). The later CT image (b) shows lower lung volumes, with increased areas of posterior and basilar airspace consolidation, findings consistent with ARDS. Areas of ground-glass attenuation have also increased in extent. (d) Close-up view of the anterior right lung demonstrates hemorrhagic necrosis and cystic dilatation. Inset shows a ruptured bleb (arrow) in the anterior visceral pleural surface of a formalin-fixed specimen. (e) Photograph of a parasagittal section of the left lower lobe (formalin fixed for 3 weeks) demonstrates a well-circumscribed, wedge-shaped pale infarct.



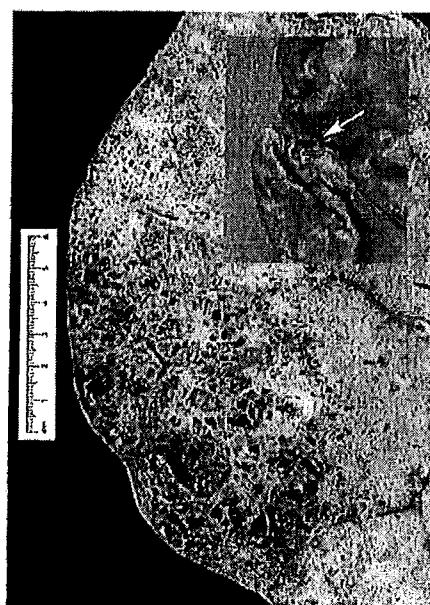
a.



b.



c.

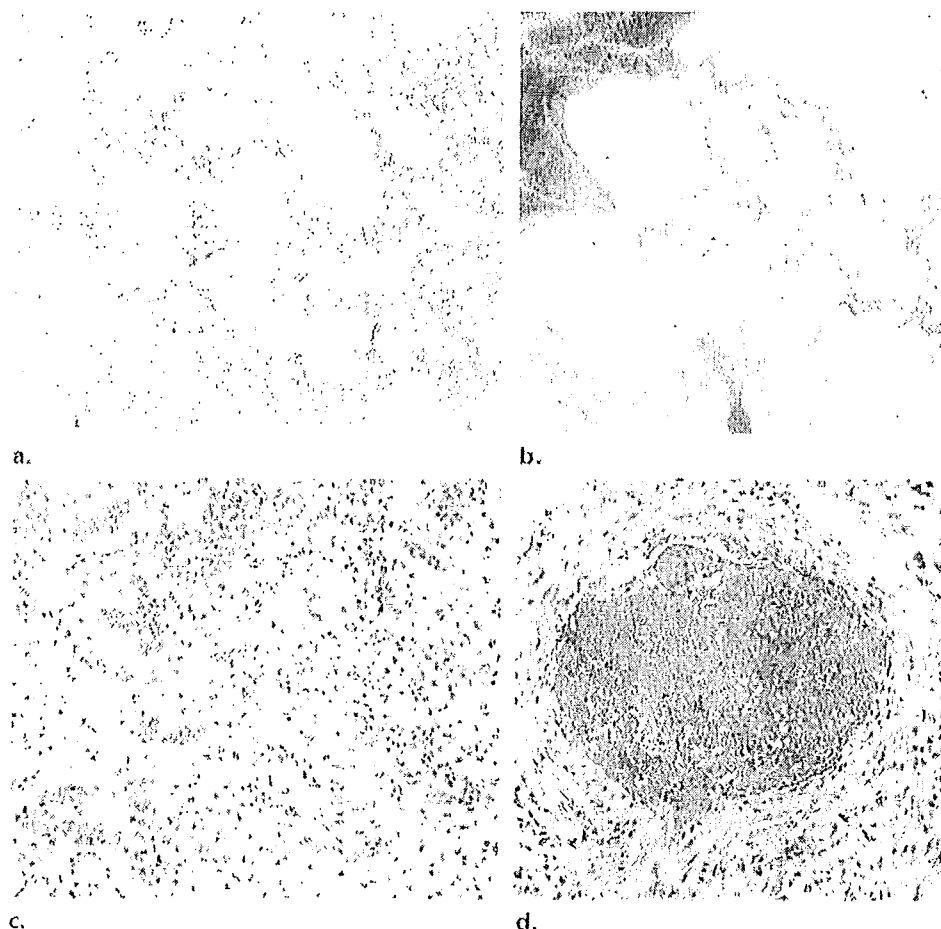


d.



e.

Figure 4. (a) Photomicrograph (original magnification, $\times 40$; trichrome stain) shows typical changes of diffuse alveolar damage with hyaline membranes and collapsed alveoli. (b) Low power view (original magnification, $\times 12$; hematoxylin-eosin stain) of a pneumatocele shows coagulative necrosis and dilatation of the airways with hemorrhage. (c) Photomicrograph (original magnification, $\times 100$; hematoxylin-eosin stain) reveals prominent bronchiolar metaplasia in the areas of alveolar damage. (d) Photomicrograph (original magnification, $\times 200$; hematoxylin-eosin stain) shows an organizing thrombus in a small pulmonary artery.



showed increased areas of ground-glass attenuation, consolidation, reticular opacities, as well as worsening cystic changes in the nondependent portions of both lungs.

Pathologic Evaluation

At postmortem examination, the lungs were edematous and firm; the right lung weighed 1200 g and the left weighed 1000 g (normal, 350–400 g). Sectioned specimens revealed interstitial thickening, progressive dilatation of airspaces, and subpleural pneumatocele formation in the anterior segments of both upper lobes and the right middle lobe, findings that correlated with those from CT imaging (Fig 3c). Pooling of blood was evident within the pneumatoceles, and at least one pneumatocele had ruptured through the pleura on the right side (Fig 3d). There was a 0.3-mm thromboembolus proximal to a well-circumscribed, wedge-shaped, pale infarct in the left lower lobe (Fig 3e).

Histologic analysis revealed acute and organizing diffuse alveolar damage throughout both lungs. The thickened lung interstitium showed predominantly lymphoplasmacytic inflammation and loose fibroblastic proliferation (Fig 4a). Dilated airspaces showed hyaline membrane formation, intra-alveolar hemorrhage, and alveolar wall infarction and collapse (Fig 4b). Complete coagulative necrosis of the alveolar walls was common to both the lower lobe infarction and the upper lobe area of dilated airspaces. Bronchioles showed regenerative changes and squamous metaplasia (Fig 4c). Numerous small arterial thrombi, ranging from 3 mm to arteriolar in size, were present with varying degrees of organization, dating them to approximately 1 week before the patient's death (Fig 4d). Notably, no embolic source had been observed at either radiologic imaging (negative results from both bilateral lower extremity compression ultrasound on hospital day 5 and CT pulmonary angiography on hospital day 9) or at autopsy.

Cultures, as well as Gram, Dieterle silver, and Gomori methenamine silver stains, for bacterial,

mycobacterial, and fungal infection were negative. Results of RT-PCR assay for 2009 influenza A (H1N1) RNA were positive, a diagnosis that was subsequently confirmed by the Centers for Disease Control from a cadaveric lung specimen.

Discussion

Influenza viruses are common and important human pathogens that are responsible for seasonal epidemics and occasional unpredictable pandemics. The deadliest pandemic in recorded history occurred in 1918, toward the end of the First World War. Infection by an influenza A (H1N1) strain killed an estimated 50 million people worldwide, with many young and previously healthy individuals dying within days of infection (1). As of this writing, the world is in the midst of another influenza pandemic, the first in more than 40 years (2). Transmission of the 2009 influenza A (H1N1) virus was declared to be in a worldwide pandemic state by the World Health Organization on June 11, 2009 (3). The 2009 H1N1 "swine" influenza A strain was first reported in Mexico, and it features gene sequences from North American and European avian, swine, and human influenza viruses (4). Epidemiologic data suggest that the 2009 influenza A (H1N1) virus exhibits relatively low virulence in comparison with the 1918 strain, but it remains a significant threat to vulnerable populations (5). Interestingly, genetic sequencing of the 1918 H1N1 strain from tissue samples that were archived at the Armed Forces Institute of Pathology has contributed to the understanding of this important pathogen (6).

Evolution has shaped the influenza virus to be adept at infecting its multiple hosts. To enter and exit from target cells, the influenza virus uses its surface proteins hemagglutinin, neuraminidase, and matrix 2. Hemagglutinin binds to and neuraminidase cleaves sialic acid cell surface receptors. Variability in cell type binding of the hemagglutinin protein contributes to the differences in virulence and transmissibility among different influenza strains. There are 16 main subtypes of hemagglutinin (H) and nine subtypes of neuraminidase (N), which lead to such classifications as H1N1 2009/influenza A. The antiviral drugs oseltamivir (Tamiflu; Roche, Switzerland) and zanamivir (Relenza; GlaxoSmithKline, United Kingdom) bind to and inhibit neuraminidase. Older antiviral agents amantadine and rimantadine block matrix 2 proteins, but many influenza strains have developed resistance against these medications. Influenza is an enveloped negative

sense RNA virus of the family Orthomyxoviridae and contains seven to eight gene segments. It is a low-fidelity replicator. The viral RNA polymerase lacks proofreading ability, resulting in a high mutation rate of 1×10^{-3} to 1×10^{-8} base pair substitutions per site per year (7), which leads to a gradual change of the viral cell surface proteins known as *antigenic drift*. Exchange of gene segments between strains causes *antigenic shift* and leads to sudden jumps in viral pathogenicity. The influenza A virus infects wide varieties of warm-blooded animals, including birds, swine, horses, and humans, whereas influenza B and influenza C viruses almost exclusively infect humans and are also implicated in epidemics (8). The large, dynamic reservoir of influenza A subtypes in animals, as well as their evolutionary adaptability, help produce new influenza strains that cause new epidemics and pandemics.

Clinical manifestations of influenza-like illness range from asymptomatic infection to mild upper respiratory illness, viral syndrome, diarrhea, and severe pneumonia to acute respiratory distress syndrome (ARDS) and to progression to multi-organ failure. Populations at increased risk for morbidity and mortality include the very young and elderly, the pregnant, those with comorbid chronic cardiopulmonary conditions such as asthma, and the immunocompromised (9).

In early stages or in mild cases of influenza infection, chest radiographs can appear normal (10,11). Viral pneumonias commonly manifest with patchy or diffuse areas of ground-glass opacity with or without consolidation (12). Spread of infection and inflammatory exudate in the air-spaces and along the bronchovascular bundles may produce a reticular or reticulonodular pattern. Multifocal areas of airspace opacities can rapidly become confluent on serial chest radiographs, and these imaging findings reflect combinations of diffuse alveolar damage, hemorrhage, and organizing pneumonia, with possibly superimposed secondary bacterial infection in later-stage disease (8,13). Pleural effusion is often absent (12).

CT, compared with radiography, is more sensitive in the evaluation of early-stage airspace opacity (14). Mollura and colleagues (15) described peripheral areas of ground-glass opacity as being the main radiologic finding in a case report of fatal 2009 influenza A (H1N1) pneumonia. Ajlan et al (16) evaluated seven patients and found areas of ground-glass opacity and consolidation with a predominantly peribronchovascular and

subpleural distribution. In their review of radiographs and CT images from 66 patients, Agarwal and co-workers (11) reported that initial chest radiographs appeared normal in more than half of patients and that in patients in more severe stages of infection, the most frequent pattern was bilateral alveolar disease with predominance in the lower and central lung lobes. They also identified pulmonary emboli in five of 14 patients who were admitted to an intensive care unit.

The well-circumscribed, wedge-shaped organizing infarct observed in this case bears a striking similarity to the peripheral wedge-shaped opacity seen at CT in other studies (13,15). The imaging findings in this case fall within the range of abnormalities previously reported, and in all of these reports, tree-in-bud opacities and lymphadenopathy were notably absent.

In isolation, radiologic findings of peripheral, scattered areas of ground-glass opacity are not specific for influenza pneumonia and can indicate multiple infectious and noninfectious pulmonary parenchymal processes, which include viral and atypical infections, alveolar hemorrhage, desquamative interstitial pneumonia, nonspecific interstitial pneumonia, hypersensitivity pneumonitis, eosinophilic pneumonia, pulmonary edema, drug toxicity, and ARDS. Imaging findings are most useful in the context of clinical symptoms, contact history, and laboratory diagnosis. The sensitivity of DFA tests for 2009 influenza A (H1N1) infection is generally lower than that of RT-PCR, with sensitivities ranging from 47% to 93% versus 86%–100%, respectively (17). Although there are reports that the 2009 influenza A (H1N1) strain is developing resistance to these agents, the neuraminidase inhibitors oseltamivir and zanamivir decrease the severity and duration of symptoms, if given early in the disease course and especially if given within 48 hours of symptom onset (18).

In severe infection, pathologic changes of influenza pneumonia include tracheobronchitis, alveolar necrosis with hemorrhage, hyaline membrane formation, and small vessel thrombosis with foci of parenchymal and pleural infarction and cystic change (8); all of these characteristics were evident in this case. The small arterial thrombi noted at autopsy, although not seen at CT pulmonary angiography 1 week before death, may have been below the detection threshold of the CT study (which was mildly limited by respiratory motion) or may have developed in the interim.


Pulmonary thromboembolism and infarction have been reported in cases of influenza pneumonia from the 2009 and earlier pandemics (8,13). The prominence of pulmonary thromboembolism and infarction in this case may be related to hypercoagulability, which has been reported elsewhere in patients with pandemic influenza pneumonia (11). Such a mechanism may provide a clue as to why some higher risk groups are more likely to suffer severe disease, and further research in this direction is needed. The advanced degree of parenchymal and pleural damage associated with infarction predispose to formation of cysts, which may rupture with positive pressure ventilation and cause extra-alveolar air to collect within the bronchovascular interstitium and to track centrally into the hila and mediastinum (the Macklin effect) (19,20). In ARDS, the dependent lung regions (usually posterior and basal) tend to collapse, and the lungs are heterogeneously stiff and noncompliant. Alveoli in the nondependent portions of the lungs, located anteriorly in the supine patient, are more susceptible to overinflation and rupture. Free air can also track peripherally, toward the subpleural interstitium, and rupture through the visceral pleura, causing pneumothorax. From the mediastinum, air can further track into the fascial layers of the neck, continue into the subcutaneous tissues of the chest and abdomen, and dissect through the diaphragmatic hiatus and into the retroperitoneum and mesentery, leading to pneumoretroperitoneum and pneumoperitoneum. Pneumomediastinum and pneumothorax can lead to further hemodynamic and pulmonary compromise (20). Pneumatocoeles associated with complete infarction may also form independent of mechanical ventilation, a characteristic that suggests a mechanism for the spontaneous pneumothorax observed in victims of the 1918 pandemic (21).

In summary, the pathologic and imaging findings in this case are consistent with 2009 influenza A (H1N1) infection that progressed to pneumonia, diffuse alveolar damage, and ARDS. Clinical management was further complicated by pulmonary interstitial emphysema and by subsequent development of pneumomediastinum, pneumothoraces, and subcutaneous emphysema. Whereas most 2009 influenza A (H1N1) infections in healthy individuals are self-limited, it is not entirely clear which pathologic factors caused the progression to fatal disease in this case and in other cases. Contributing factors in this case likely include the patient's pre-existing asthma and relatively young age, which is associated with lack of prior exposure to and immunologic immunity against influenza

A (H1N1), a strain that has not widely circulated in humans since 1957 (22). Another contributing factor may have been the administration of corticosteroids early in the disease course, without concurrent antiviral therapy, for presumed asthma exacerbation, producing immunosuppression that may have resulted in more severe infection. Corticosteroids deplete circulating leukocytes, suppress lymphocyte proliferation in response to antigens, and are associated with increased plasma viral titer (23,24). On the other hand, administration of steroids has been reported to decrease mortality in cases of severe avian (H5N1) influenza and severe acute respiratory syndrome (SARS), possibly by dampening an exuberant systemic inflammatory response incited by these viruses later in the disease course (24). Secondary bacterial infection, which has been shown to be an important comorbid condition in cases of fatal influenza (8,13), was absent in our case, most likely due to broad-spectrum antibiotic treatment. It has been suggested that genetic differences in immune response may also be a factor in disease severity (25). Clearly, despite the current detailed understanding of the pathologic and radiologic findings in influenza infection, further research into the pathogenesis of this important virus is essential to help reduce the morbidity and mortality from this, and future, influenza pandemics.

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Patricia Levinson recounts the story of her fiancé Christopher's battle against H1N1. His case was published in the Journal RadioGraphics.

Love, Loss, and the H1N1 Flu

By Patricia Levinson

The voice of my grief counselor was strong and appropriate. "Tell me," she said, "what does someone who dies of the flu look like?"

Even looking through the lens of my own illness and profound grief, her words gave me pause.

On one hand, a person who dies of the flu doesn't look like my 56-year old, 6 foot, handsome, fit fiancé, with whom I had kayaked on the San Francisco Bay the very day before he came down with the flu. On the other hand, this wasn't

just any ordinary flu. This was the H1N1 flu, and both Christopher and I had asthma, putting both of us squarely into a major known high risk group for severe complications.

But that last day we kayaked on the Bay, we were just two ordinary, middle-aged people, desperately in love, looking forward to dinner with our daughters, who were home for the summer. The next day, Christopher came down with what we soon learned was the H1N1 flu. Two days later, I got it. It happened so quickly that we

never even got the kayaks off of the car. Instead, we catapulted into a world of antibiotics, steroids, breathing treatments, and an arsenal of asthma medications. There were multiple visits and calls to the doctor.

Within days, it seemed that we were at least as sick as either of us had ever been. In less than a week, Christopher's illness had progressed into pneumonia, and he was admitted to the hospital by ambulance straight from the doctor's office. Just over two weeks later, he died from respiratory complications of the H1N1 flu.

Getting back to my grief counselor's question, at least one person who died of the flu looked just like my 56-year old, 6', handsome, fit fiancé who happened to have asthma. And at least one 54-year old person, who also happens to have asthma, didn't die from the H1N1 flu. She looks just like me. It took months, but the same medicines that failed Christopher ultimately worked for me. Some of the finest doctors in the world still can't explain it, and neither can I.

What I do know is this. He was the love of my life and I lost him to the H1N1 flu about a month before we were going to get married.

I met him on the most unlikely of personals websites, craigslist. We were two middle-aged people, both of whom had about given up on finding a partner. And then, right in the middle of our ordinary lives and with absolutely no warning at all, it happened.

That first coffee date that lasted two and a half hours. The second date, kayaking in Monterey, and the picnic on the beach. The third date when he asked me to marry him. We used to laughingly tell people that I was the less impetuous one, not actually accepting his marriage proposal until the fifth date when I moved in with him.

But in reality, neither one of us thought that we were impetuous. Instead, we were absolutely convinced that we'd found the person of our dreams. That, we thought, was one of the benefits of middle-age - by now, you knew yourself well enough to know exactly what you were looking for. And if you were fortunate enough to find the right person, you shouldn't waste a moment. Christopher and I did many things together, but wasting time was not one of them. After all, life is short. At the time, we reckoned we'd already lived over half of it. The fact that we recognized what we had found with each other and followed our hearts from the very beginning is one of the greatest gifts of my life.

Years ago, when I was first divorced, a woman friend told me that I should look for a rich man, one who could take me to exotic places and out to fancy dinners. While I like exotic places and fancy dinners, I told her that I'd forgo them forever in favor of sitting at a neighborhood dive across the table from a man who made my heart sing. Christopher wasn't a rich man, and he died before we had time to go to any exotic places. Fancy dinners out were never our thing. But we often danced as we cooked dinner, and we sat across the table sharing everything from the daily grind to our deepest secrets. A waitress at a neighborhood restaurant once told us that she'd never seen a couple like Christopher and I, so

obviously devoted to one another, sit in one of her booths. I had never loved like that and neither had he. The last time that we dined out was at a taqueria just prior to dropping our kayaks in the bay that day in July. We were both wearing our wet suits.

I remember Christopher's arrival at the hospital, by ambulance, and settling him in his room. His ICU nurses were impressed that he was concerned about the stress that his hospitalization was putting on me. After all, I was sick too. Sometimes I wonder if my being so sick was the universe's way of insulating me from Christopher's illness as it unfolded in the ICU.

I once got a phone call from his ICU nurse. He'd written a note and asked her to call me, just to tell me that he loved me. I told the the nurses and doctors that he just had to get well, I'd waited my whole life to find him.

"Two days before he died, the last time that he looked at me, he started to cry. I suspect he knew that the end was imminent before I did."

I remember our last conversation, several days after his admission to the hospital, and right before he went on the respirator. Among other things he told me that day, he said that he was not afraid and that he was grateful for such world class medical care. Two days before he died, the last time that he looked at me, he started to cry. I suspect he knew that the end was imminent before I did.

I remember the decision to honor the "do not resuscitate order" that Christopher and I had talked about not so long ago. I held Christopher's hand, and talked to him, as he took his last breath and his heart beat for the very last time. I remember the quiet of the ICU room and the delicate and precarious balance of devastation and support from his daughters who stood with me that morning. At ages eighteen and twenty one, they were at least as brave as their father that day. We gave the hospital permission for an autopsy, specifically for the purpose of learning more about the H1N1 flu. Christopher would have wanted that. He was an Emergency Preparedness Instructor for a living.

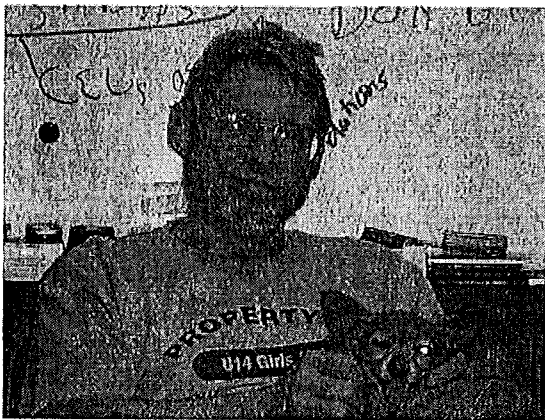
I remember very little of those early days without him. I tried as best as I could to survive emotionally, while at the same time respecting my body's physical need to recover from what the H1N1 flu had done to me.

I remember feeling thrust into the role of the matriarch of our blended family, and during that first

month having three of our daughters start school, one daughter transition to a new job, and one daughter cope as best she could as a stay-at-home mom with young children.

I told the girls that the last place their Dad would want us to be is marooned by the side of the road. We owed it to Christopher to get through this catastrophe the best way that we could. I told them it would be anything but easy, but that we would do it together.

There were days when I'd walk into a room, sit down, and hours later, not know where the time went. Some days, I asked people not to bother to call me because I didn't have the words to talk to them. Some folks, like my hair dresser, understood implicitly. He opened the salon early one day to cut my hair in private. Then, there were the people who told me to "get over it," "be cheery," or, that, "with time, I'd find another Christopher to love again." Though well meaning, these people were completely ignorant of the depth and nature of my grief. The charitable part of me believes it was their way of saying that they wanted the old Pattie back.



It's been almost a year since that beautiful July day that we took to the Bay in the kayaks for the very last time. Our three college-aged daughters have completed the school year. Once again, girls are home for the summer. One of our daughters is almost done with her Americorp service. Christopher's only son-in-law has illustrated a book, to be published in

the fall, and has dedicated the book to Christopher's memory. One of Christopher's granddaughters finished kindergarten. I survived a corporate acquisition at work.

Meanwhile, Christopher's case has been published in a major medical journal. Just last week, one of his doctors wrote to tell me that Christopher's autopsy helped with their understanding of H1N1. All this would have pleased Christopher greatly. That was the emergency preparedness instructor in him.

It's been nine months and I still can't sleep on his side of the bed. I have yet to get back in a kayak. I miss him terribly. Some days I still get lost in my grief. But, these days, I can look out at the ocean without crying. I can go to our favorite restaurants

"And, just how ordinary is it to come down with the flu?

Yet, in extraordinary circumstances, people like my Christopher die from it."

and enjoy dinner out. I travel to places that we went together and remember the good times. Ever so slowly, our family, friends, and I are creating new memories.

The overlay of Christopher is still there, but the edges have become less jagged and sharp. Forget closure, I don't think it happens. What I do think happens is that you have to re-emerge in life.

I've come to realize that out of ordinary lives come extraordinary experiences. Christopher and the love that we had together was one of the extraordinary ones. Yet, we met on the internet, and we first laid eyes on each other at a neighborhood coffee shop. These days, it doesn't get any more ordinary than that.

And, just how ordinary is it to come down with the flu? Yet, in extraordinary circumstances, people like my Christopher die from it.

Many months later, in some ways, my life has returned to the ordinary. It's a new ordinary life though, transformed by a love so real and strong and a death so out of sequence and seemingly random.

These days, I smile when I think of what some people thought was our impetuous love affair. People know now, what Christopher and I knew back on that third date when he asked me to marry him. They tell me that for nine months, we had what many people don't have in a lifetime. They tell me that it's rare to see people love like we did.

The only regret that I have from my life with Christopher is that we didn't have the gift of more time together. And, though it is a very bitter pill to swallow, I realize how incredibly fortunate he and I were to have had the time that we did. ■

Patricia Levinson is a technical writer who lives in Mountain View, California. She enjoys the outdoors, hiking, kayaking, and cooking. She misses Christopher every day and reckons that she always will.

The case report is available online: Guo HH, Sweeney RT, Regula D, Leung AN. "Fatal 2009 Influenza A (H1N1) Infection, Complicated by Acute Respiratory Distress Syndrome and Pulmonary Interstitial Emphysema" Radiographics. 2010 Mar;30(2):327-33. 2010 Jan 12.

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Perspectives

Through the Patient's Eyes: New Doctor

F.R. Burdette

New insurance. Another HMO—second in my first year of Medicare. I can't remember how many primary care physicians I've had since they started calling them that.

I arrive 20 minutes early for the first appointment with the new PCP, aware there is a woman waiting to thrust a clipboard and forms at me. Where do they find all of them—the forms and the women? I am still writing and making check marks 10 minutes after my appointment time. How many different ways are there to probe for employment, a working spouse—potential additional insurance coverage?

Age? Date of birth? Why both? She's already made copies of my driver's license and insurance card. Normal weight? 200. Weight gain/loss in past year? Plus 10 pounds. Height? At my best, I was 6 foot 3/4 inches; now I barely measure five eleven and a half. I hate to admit I'm not 6 foot anymore so I write "6'0." Maybe they won't catch it.

Married? Single? Widowed? Divorced? What's the difference between divorced and single? What is the need to know? Do single organs fail or function differently from divorced (or widowed or married) organs? Will it mean I'm strange if I say "single"? Or a failure if I check "divorced"? I feel single. I've been divorced twice, but I've been single three times—in all, a couple more years than I was married. I like feeling "single." I check that. The relationship of my emergency contact is "son" but I'm single. Does that matter anymore?

There are the standard questions about medications, allergies, illnesses, and surgeries. Here's one I haven't seen before: Sexually active? Not very. Sex of partners? Clearly they mean partner's sex. Wonder what the grace period is? I check "not sexually active"—reluctantly. It's not like I've given up hope. Sex of partners: "N/A."

Then the biggie. I like the way the Blood Bank asks it: Have you had sex with a male, or someone who's had sex with a male who has sex with other males, since 1976? (Something like that anyhow.) I'm always tempted to ask which month.

The rest aren't quite so invasive. Yes, I have noticed a loss of vision and hearing—seems like memory too. Yes, I have ringing in my ears, insomnia, and I snore. I also have shortness of breath, pains in my calves—and other assorted pains they don't ask about. There are a lot of things I don't like to admit even to myself but I keep checking them off. I really thought I was pretty healthy when I came in. I remind myself I'm not sick; I'm just here for an initial visit, referrals to my dermatologist and ophthalmologist, a new thyroid prescription, and a flu shot.

The good news is I stopped smoking and drinking and I have a regular exercise program. They ask about my Living Will and Durable Power of Attorney for Healthcare. I've brought copies of those and my organ and whole body donation and Do-Not-Resuscitate Order. Now the wait.

Over an hour past the appointed time, I am weighed in—214.80 with clothes. They don't check my

height; I get by with that. They lead to me an exam room where the doctor joins me shortly. From the table, I look down at the top of his head as he reviews the list I brought along of things I thought were pertinent; his remarks are limited almost entirely to "fines," "very goods," and "excellents." I scrutinize him more thoroughly than he scrutinizes me. He's very bald but his red facial hair is thick and dark. He must be young enough that he will still be around when I need him, but that doesn't seem important in this day of revolving doctors.

He doesn't take my blood pressure or listen to my heart. He doesn't examine me—or look at me closely. The snap of latex gloves is conspicuous by its absence. Even my prostate feels slighted. He hasn't touched me except to shake my hand. No eye contact either.

He doesn't look at the forms I filled out. What are they going to do with those? Was it only that woman who was curious? In less than 10 minutes I have the referrals and prescription and am headed to the lab for a thyroid check on my way out.

The phlebotomist tells me I made a good choice of doctors. Maybe. Maybe this is patient-directed medicine. Maybe I'll like him if I get to know him. Maybe I should have brought a form for him to fill out. The jury is still out. I mean how can I tell? Actually I chose him for the proximity of his zip code. And he did originate the referrals and give me the prescription I asked for. That's all I really needed today—that and the flu shot I forgot to ask about and he didn't mention either.



F.R. Burdett walks the seawall and writes in Galveston, an island off Texas, in the Gulf of Mexico. His PCP is located 30 miles inland.

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The Role of the Patient in Medicine---A personal perspective

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At age 15, I was on the Grand Island High School track team and an avid athlete. As my second season progressed, I was periodically awakened in the night by a crushing pain in my chest, which I disregarded, attributing it to weight lifting. Over time, however, I also began having a hard time breathing whenever I exerted myself. I felt like something was restricting my heart from beating, and eventually I had to quit track practice and rest. After a few weeks, the pain in my chest worsened and I found myself being rushed to the Children's Hospital of Buffalo.

By the time I arrived at Children's, I was doubled over from the pain in my stomach and chest. After receiving a physical exam from the emergency room resident, I was immediately introduced to the concept of a nasogastric tube. The nurse pumped out of my stomach what seemed like gallons of dark red blood. I recall a sense of relief that the hospital staff had found the problem and that I would be able to return to practice soon. But that wasn't the case.

I was admitted to the hospital, began vomiting blood every few hours, and over the course of the next two days underwent a barrage of tests. I remember very clearly the day the chief of pediatric surgery and a group of short and long-coated doctors entered my room to tell me my diagnosis.

"You have tumors in your chest and stomach, Jimmy," I was told.

"Are they malignant or benign?" I remember asking.

"I am afraid they are malignant, and we have to go in and take them out."

Curious to know what any human being in my situation would want to know, I asked, "Where did they come from?"

The surgeon's response was one I will never forget: "I am the best at what I do. I have written books and trained at the Mayo Clinic. All I can tell you is that you have had a run of bad luck, Jimmy."

And my luck didn't necessarily improve.

After starting my second year of medical school this fall, I sent for my medical records. When I sat down to read all about the 17 hours of surgery I underwent and the treatment that followed, I felt a mixture of emotions. One moment, it was almost as if I were outside looking in, reading the chart of a hospital patient that my preceptor wanted me to see; yet, the next moment, it was as if I were viewing things from the inside looking out, understanding, perhaps for the first time, what the words "the patient" really mean.

I elect to provide here a few details about my treatment based on what I learned from my medical records. In reference to a biopsy of a 10 by 20 cm mass in my chest, I found the following description: "Pathology came back as a malignant process. Exact tissue type unknown. The patient was then taken to the operating room where he underwent Whipple procedure for his

pancreatic mass and a repeat right thoracotomy for excision of his mediastinal mass. Of significance is the fact that there was question of injury to the phrenic nerves which did compromise his postoperative course."

At first when I read this, I had difficulty comprehending that these masses had been *mine*. I wasn't sure who they belonged to, but they certainly weren't *mine*. However, I did comprehend the reference to my postoperative course being "compromised" since I do remember spending the next two weeks intubated. This was necessary because I couldn't breathe on my own due to the fact that my mediastinal mass had attached to my phrenic nerves. (I have since learned that the phrenic nerves innervate the diaphragm. If injured, they tend to leave "the patient" with an elevated diaphragm, which I have to this day.)

After about a month or so of recovery, I had to begin the real battle: chemotherapy. One day prior to beginning this phase of my treatment, I was finally given my diagnosis of non-Hodgkin's lymphoma after an ensemble of pathologists finally figured out what my cancer was. It was a huge shock that day to also learn that I would have to wear a Hickman catheter for a year in order to undergo 12 months of chemotherapy. Being that it was the middle of June and my parents had just put in a pool, having a tube coming out of my chest was not my idea of appropriate summer attire.

I thought the surgery was bad, but it pales in comparison to what chemotherapy feels like. I remember my first treatment well. My oncologists, who are all dear to me, entered the room with a tray of enormous syringes filled with colorful medications. They did their best to list the possible side effects of the medications to my family and me: "Well, this medication has been known to cause stomatitis, cardiotoxicity, seizures, leukopenia, alopecia, nausea/vomiting. . ." Hearing this, I began to wonder what the hell I was thinking when I signed the consent form!

Many people have asked me what chemotherapy feels like. Depending on who's asking: a patient about to begin treatment, or a curious classmate? My answer varies. Basically, the feeling you have when you're undergoing chemotherapy can be conveyed by asking a person to imagine how he feels when he has a bad case of the flu. Then, ask him to magnify that feeling by five while simultaneously coming to the realization that it's not going to subside for 12 months. Finally, add to this the fact that there are no guarantees the drugs will work (about a 60 percent chance), and if they don't, you may have to start another regimen all over again after that.

Having the opportunity to be a medical student after being a cancer patient is one of the most incredible life experiences imaginable. Among other things, it seems to finally lend meaning to what happened to me as a teenager. It also helps me realize that there's a big difference between reading in a journal about survival rates for a disease and having to face the statistic yourself. Although I had to wait until my second year of medical school, I have finally begun to see my cancer experience through the eyes of medicine. I understand the meaning of terms like "elevated LFTs", "invading mediastinal mass" and "jaundice" as a medical professional, but also as a patient.

Now, as I begin to work with patients as a medical student, I find that I am using what I learned as a patient. Yet I am also aware of and have respect for the fact that every patient's experience is unique in many ways. Therefore, one thing I have worked to do is silence the thought "I know" that goes off in my mind when a patient remarks about postoperative pain, persistent nausea, or what it is like being intubated. While there is always the sense that I truly do understand more of what they are talking about, I also know it's important for me to learn how to listen because being a good listener, I feel, is one of the best skills a doctor can have.

Thank you for allowing me to share with you this medical student's perspective on the role of the patient in medicine.

James J. Mezhir is a second-year student at the University at Buffalo School of Medicine and Biomedical Sciences.

(Reference: <http://www.oncolink.org/coping/article.cfm?c=6&s=31&ss=76&id=255>)

Virtual Mentor

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Clinical Case

Controlling Diabetes

Commentary by Robert P. Hoffman, MD

Sharon Smith was diagnosed with type 1 diabetes at age 11. Under the watchful eye of her parents, Sharon was an active teenager, participating in high school sports and extracurricular activities. In college, she continued with soccer and diligently controlled her blood sugar, following the same insulin regimen she had begun in her mid-teens. After college, Sharon moved across the country to pursue graduate studies. To help pay her living expenses, she began working 4 days a week as a waitress. One night as her shift was ending she noticed that her hands were shaking as she was replacing glassware, and she later passed out. The restaurant staff, unaware that she was diabetic, called 911 for assistance.

Sharon was admitted to the hospital, and Dr Stone—an endocrinologist—was called. Dr Stone had seen Sharon quite a few times since her move to the city about 6 years earlier, usually after emergency episodes. When he first met Sharon, she was moderately overweight and had elevated cholesterol levels. Examining Sharon's medical records at that time, Dr Stone noted that these developments were recent. Since their initial clinical encounter, Dr Stone had encouraged Sharon to lose weight and had explained the possible complications for someone who had had type 1 diabetes for more than 5 years. Sharon claimed that she had tried to lose weight, but found it impossible to balance glycemic control with weight loss. Adding to her frustration were a bum ankle, intense graduate coursework, and her waitressing job, all of which prevented her from exercising as regularly as she had in college.

Dr Stone has attempted—numerous times—to modify Sharon's insulin regimen and provide her with a clearly laid-out dietary plan to help her lose weight and control her blood sugar. He believes some of Sharon's noncompliance might be due to depression or other psychological factors and referred her to a counselor who had worked successfully with many of his patients with diabetes. Sharon saw the counselor once but refused to continue, stating that she had neither the time nor the money to attend regular sessions. Despite Dr Stone's continued efforts, Sharon has been admitted to the hospital a number of times with recurrent diabetic ketoacidosis.

Sharon repeatedly tells Dr Stone that she understands the consequences of ignoring his advice, and she constantly expresses her annoyance with this disease, especially in relation to her living situation. Dr Stone is sympathetic to Sharon's plight—she is young, busy, and burdened with a disease that will be with her for the rest of her life. But he is frustrated by her lack of responsibility; she doesn't adhere to the diet, she sometimes cancels appointments at the last minute, and, he suspects, she has begun drinking alcohol. When he confronted Sharon about her behavior during her latest

hospital stay, she shrugged and responded, "C'mon, Dr Stone. It's not that bad. You always pull me through."

Commentary

Study after study has demonstrated that many patients—adults and adolescents, alike—with type 1 diabetes do not follow through with the numerous aspects of their diabetes care [1]. Sharon's failure to appropriately follow diabetes management recommendations may be due to a variety of problems including subclinical eating disorders, depression, fear of hypoglycemia, feelings of failure due to recurrent hospitalization, or dislike of injections and glucose monitoring.

How Dr Stone reacts to Sharon's situation will be reflected by the terminology he uses when discussing his concerns and by who he thinks is in charge of managing Sharon's diabetes. According to the American Heritage Dictionary, to adhere means to "to carry out a plan, scheme, or operation without deviation" and to comply means "to act in accordance with another's command, request, rule, or wish." Thus, if Dr Stone believes the patient should follow his rules, and she does not, he will consider her to be noncompliant; if he believes she must help develop her own treatment plan, and she is unsuccessful, he will then view her as being nonadherent. This difference between compliance and adherence plays a critical role in answering several questions regarding Sharon's care.

Is Dr Stone obligated to continue to serve as Sharon's endocrinologist?

If Dr Stone uses the language of compliance to describe Sharon's actions, then he is not obligated to continue to care for her. Simply stated, she has not followed his prescribed medical plan and recommendations, and thus he is wasting his time caring for a patient who doesn't follow through. In this situation he is only obligated to take care of her in an emergency if he is the best available physician to do so. Once the crisis is over he can give her names of other health care professionals in the area who can care for her diabetes, as her health care coverage allows.

This course of action puts Dr Stone in a position of power over Sharon, and its ultimate purpose may be to feed Dr Stone's ego. He would do well to consider that he is most likely noncompliant in some area or areas of his own health care [2] and to remember the Golden Rule: "Do to others what you would have them do to you."

If, instead, Dr Stone uses the language of adherence, his obligation to Sharon is different. He will have to help her develop a treatment plan for controlling her diabetes that is compatible with her lifestyle. The goal of diabetes management should always be to train and encourage the person who has the condition to assume control and responsibility for his or her treatment [3]. In this situation Dr Stone must provide Sharon with the best possible evidence-based medical advice and the basis for this advice. This approach reduces his paternalism while allowing Sharon to make choices based on his recommendations.

In this scenario Dr Stone's decision to continue or discontinue his care of Sharon is based on whether he believes he is the best person available to help her manage her

diabetes. If he feels that his frustrations with Sharon or her emotional dependence on him interferes with helping her to develop and follow an effective diabetes treatment plan, then he must tell her why this is the case and offer to assist her in finding a professional who will help her. This future care may or may not be under Dr Stone's supervision, depending on the availability of allied health care professionals such as diabetes nurse educators, dietitians, and psychologists.

What responsibilities does Sharon have to manage her diabetes?

Ultimate responsibility for Sharon's diabetes care clearly falls on her. She appears to be mentally competent; she is attending graduate school and holding a job. This is not a situation in which Dr Stone has the right, responsibility, or ability to carry out medical care independent of Sharon's wishes [4].

Sharon's obligations when she was under the pediatric care team would have been much different. The responsibility for managing her diabetes would legally have fallen to her parents until Sharon reached her eighteenth birthday. Prior to her turning 18 the physician would have been required by the state to report Sharon's parents' failure to assure that she got proper diabetes care. In part due to Sharon's minor status, the patient-physician relationship would have been much more paternalistic when Sharon was first diagnosed with diabetes, although one hopes that, even at age 11, there was an attempt to involve her in some of the decisions regarding her treatment plan. If this did not happen, particularly as Sharon became an older adolescent, her current nonadherence may be traced back to her overdependence on others to keep her safe. At the other end of the spectrum, adolescents given *excessive* autonomy by their parents also have poor metabolic control [5].

Unfortunately, patient transition from the more paternalistic pediatric care model to the more autonomous adult model is not always well handled, due to factors both within and beyond the control of the physician or patient. These include insurance company and hospital regulations that govern the age of patients allowed to be seen by pediatric and internal medicine subspecialists, decisions regarding employment, advanced education, and changes in location. Because of these factors many young adult patients with diabetes are in a medical "limbo" when it comes to getting their diabetes care. It was thus critical for those managing Sharon's diabetes during her adolescence to ensure that she had the skills to take over that responsibility independently by the time she left pediatric care and to assure that she was aware of the importance of regular close followup and where this could be obtained.

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Discussion Questions:

1. Have you ever been a patient? What are the positive and negative aspects of your experience?
2. What are the differences between the two accounts of the H1N1 case?
3. What are some common characteristics of patients?
4. What are some common barriers to empathy and compassion in the physician-patient relationship?
5. Which do you think is more important, technical expertise or compassion?
6. Is it acceptable for a physician to be proficient and skilled, but rude to staff and patients?
7. Numerous studies have demonstrated a loss of compassion through the medical training process. Why does this occur? How can we prevent it?

SEPTEMBER 12

Minors: Consent and Confidentiality Issues (Dr. Cathi Badik)

PLENARY AND SMALL GROUP DISCUSSION

Objectives:

1. Describe appropriate measures for obtaining consent for medical care for minors.
2. Identify categories of mature and emancipated minors and their role in medical decision making.
3. Explain the significance of confidentiality when caring for minors.
4. Discuss scenarios in which confidentiality may be appropriately breached when treating minor patients.
5. Recommend a balanced approach to the medical care of minors.

Required Readings:

“Ethical Issues in Pediatrics”, in: Lo, Bernard: *Resolving Ethical Dilemmas, A Guide for Clinicians*, pp. 267-277.

“Improving Access to and Utilization of Adolescent Preventive Health Care: The Perspectives of Adolescents and Parents”, Tumaini R. Coker et al: *J of Adol Health*. 47 (2010) 133-142.

Assignment:

No assignment.

Case

A 14-year-old girl presents to the Emergency Department with complaints of fever, abdominal pain, and vaginal discharge. The patient requested that her parents not be contacted regarding her medical care. During the interview, the patient noted a 3-day history of increasing abdominal pain, anorexia, vaginal discharge, and subjective fever. She initially denied sexual activity. Physical examination revealed temperature of 101.5 F, other vital signs stable. Abdominal examination revealed significant suprapubic tenderness without mass or rebound tenderness. Pelvic examination revealed cervical motion tenderness and copious purulent vaginal discharge. These findings were judged by the treating physician to be consistent with pelvic inflammatory disease, most likely caused by a sexually transmitted organism, such as gonorrhea or Chlamydia. On further discussion with the patient, she reluctantly admitted to unprotected sexual intercourse. She again affirmed her desire that no information be released to her parents. During her ED stay, the patient's mother called to request information, “How is my daughter doing? What's wrong with her? I'm worried about her.”

Original article

Improving Access to and Utilization of Adolescent Preventive Health Care: The Perspectives of Adolescents and Parents

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Abstract

Purpose: To examine the perspectives of publicly insured adolescents and their parents on ways to encourage adolescent utilization of preventive health services.

Methods: We conducted eight focus groups with 77 adolescents enrolled in a large Medicaid managed care plan in Los Angeles County, California, and two focus groups with 21 of their parents. Discussions were recorded, transcribed, and analyzed using the constant comparative method of qualitative analysis.

Results: Adolescents and parents reported that the most effective way to encourage preventive care utilization among teens was to directly address provider-level barriers related to the timeliness, privacy, confidentiality, comprehensiveness, and continuity of their preventive care. They reported that incentives (e.g., cash, movie tickets, gift cards) might also be an effective way to increase preventive care utilization. To improve adolescent receipt of surveillance and guidance on sensitive health-related topics, most adolescents suggested that the best way to encourage clinician–adolescent discussion was to increase private face-to-face discussions with a clinician with whom they had a continuous and confidential relationship. Adolescents reported that the use of text messaging, e-mail, and Internet for providing information and counseling on various sensitive health-related topics would also encourage adolescent utilization of preventive health services. Parents, however, more often preferred that their teen receive these services through in-office discussions and clinician-provided brochures.

Conclusions: State agencies, health plans, clinics, and individual providers may consider focusing their efforts to improve adolescents' utilization of preventive services on basic structural and quality of care issues related to the clinician–patient relationship, access to services, and confidentiality.

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Keywords:

Adolescent health services; Preventive health services; Ambulatory care; utilization

National medical organizations recommend routine preventive care for all adolescents [1,2]. Although the recommended frequency of visits may vary across guidelines, from annually to every 3 years, they all reflect

the importance of addressing important health behaviors that are often established during adolescence [3]. Adolescent preventive care provides an opportunity for adolescents to receive information, counseling, and guidance regarding critical health-related behaviors that represent many of the major causes of adolescent morbidity and mortality. Decisions about these behaviors may not only influence health during adolescence, but may also have long-term effects on their health as adults. However, a substantial proportion

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of U.S. adolescents does not routinely utilize preventive care [4–7]; utilization may be especially low among African American youth, Latino youth, and youth living in poverty [4–7]. Even when adolescents do attend preventive visits, studies suggest that most of them do not receive many recommended preventive health services, including counseling and guidance on risky health behaviors [8–10].

Adolescents' perspectives on barriers to preventive care visits have been well studied [8,11–16], and several studies have proposed and examined particular strategies to improve preventive care utilization [17–20]. To develop practical strategies for increasing preventive care utilization among economically vulnerable adolescents, we need a rich and broad understanding of what adolescents and their parents think would work.

We sought to examine the perspectives of low-income adolescents on how healthcare organizations and providers can increase preventive care utilization, and to supplement these data on adolescents with the perspectives of their parents.

Methods

Eligibility and recruitment

Two study recruiters attempted to call 1,164 randomly selected households with adolescent Managed Care Medicaid enrollees in a commercial health plan (enrolled continuously for at least 12 months) living within a 15-mile radius of the plan's community resource center (the focus group site). Eligible adolescents (age, 13–17 years) had parental consent to participate and were selected to provide the desired mix of enrollee age, gender, and primary household language (English or Spanish by parent report). Among households contacted, 394 had a disconnected telephone number and 296 could not be reached after ≥ 2 attempts. Recruiters successfully contacted 474 households; 209 adolescents declined to participate, and 62 agreed to participate but had schedule conflicts. The remaining 203 were scheduled on a first-come basis until each of the 8 focus groups had at least 10 scheduled participants. Parents of teens who had already participated in a focus group were invited to participate until 24 parents were scheduled for two focus groups.

Teen groups were stratified by gender, age [13–15, 16–17 years], and household primary language; parent groups were stratified by household primary language only. We used this stratification to allow teens with varying levels of preventive care utilization to discuss sensitive topics in groups with same-sex peers and to identify specific issues for teens from Spanish primary language households. All teen focus groups were conducted in English (all adolescents spoke English fluently); one parent focus group was conducted in Spanish.

Study procedures

We conducted a review of published data on adolescent preventive health services, and then developed a focus group

discussion guide (see Table 1 for general questions; the full discussion guide is available upon request). It included questions to elicit discussion on three major topics: (1) views on and experiences with preventive visits; (2) ways in which health plans, clinics, and clinicians can help to increase adolescent access to and utilization of preventive visits; and (3) strategies that health plans, clinics, and clinicians can use to encourage teens to discuss important health-related topics during preventive visits. Each topic focused specifically on preventive visits. In the beginning of each group, the facilitator described the preventive visit in detail and mentioned that she would be discussing preventive visits only. Participants discussed multiple examples to help them understand the difference between sick and preventive visits; we reinforced their understanding of preventive visits by asking those with a preventive visit to describe it. The focus group discussion guide included general questions used in every group to elicit participants' views, without first offering specific examples. It also included a number of optional "probes" or questions to generate discussion in cases when no ideas were brought up, and to obtain parents' views on adolescent-generated ideas. The RAND Human Subjects Protection Committee approved the study.

The focus groups were held in December 2007 and January 2008; each group included 6–12 participants, lasted approximately 2 hours, and was conducted by an experienced, bilingual focus group moderator. Participants completed a brief demographic survey and received a cash honorarium.

Analysis

Sessions were audiotaped, transcribed, translated if in Spanish, and imported into a qualitative data management software program. Two experienced qualitative coders and 2 authors (T.C. and P.C.) read the first two transcripts and created codes for key points within the text. Through an iterative process, these codes were developed into a codebook using standard procedures [21]. The coders then independently coded each transcript consecutively, and discussed discrepancies and modified the codebook (with T.C.). To measure consistency between coders, we calculated a Cohen's kappa [22] using a randomly selected sample (33%) of quotes (independently coded) from each of the major themes. Kappa scores were 82%–92%, suggesting excellent consistency [23].

Next, the research team performed thematic analysis of the 1,067 unique quotations that dealt with the three major topics. The analysis was based in grounded theory and performed using the constant comparative method of qualitative analysis [21,24]. The team identified the most salient themes; these were the concepts and ideas that emerged from the quotes within each topic. Next, we examined each theme, its frequency and distribution, and patterns within and between the groups. Because we aimed for thematic representation, we present not only consensus, but also key dissenting

Table 1
Selected general focus group questions by topic

Topic 1: Views on and experiences with preventive visits

1. Who has gone to the doctor for a regular checkup?
 - a. Tell me a little about that. What was it like?
 - b. What did you think about the visit when it was over? Would you want to go back to that doctor for your next checkup?
2. Teenagers should have a regular checkup with their doctor each year. What do you think about these regular checkups? Are they necessary? What should happen during these visits?
3. What are some of the reasons that teens sometimes don't go for regular checkups? Are there things that make it hard to go or stop teens from going for regular checkups?

Topic 2: Ways to increase adolescent access to and utilization of preventive visits

Now we would like you to help us think of ways in which doctors and clinics can make it easier for teens to go to their regular checkups.

1. What could be done to make it easier for teens to go in for their checkups?

What could be done to encourage teens to go in for a checkup?

What would make a teenager go to the doctor even though it is not easy?
2. Sometimes doctors offer gifts or rewards to patients who come to regular checkups to encourage them to come. We call these incentives. For example, young children are sometimes given things like candy or stickers when they go for regular checkups and this makes them happy to go see the doctor. Do you think that incentives would work to encourage teens to go to doctors for regular checkups? Why or why not?
3. We would like you to help us think of ways to make teenagers excited or enthusiastic about going to the doctor. Let's try to name five ways to make more teens go to doctors for regular checkups.
4. Are there any other things that would make teens go in for a checkup?

Topic 3: Strategies to encourage teens to discuss important health-related topics during preventive care visits

We would like you to think about teens like yourself and tell us what teens think about getting checkups and what kind of information they might want to get from their doctors.

1. Can anyone give me some examples of questions that teens might ask their doctor?
2. What do you think about talking to a doctor about these types of things? Is that something teens feel comfortable talking about with doctors?
 - a. What would make you feel comfortable talking to your doctor about these topics? Are there things the doctor could do to help you feel comfortable talking about these sensitive topics?
3. What do you think is the best way to get information from your doctor about these types of questions? Is talking to doctors in person the best way or are there other ways that you would rather get information?
 - a. Out of all of these ways to get information from your doctor that we have talked about so far, is there one particular way that you think would work best for you?

views when available to give a more accurate impression of agreement and disagreement among participants.

Results

A total of 77 adolescent enrollees (36 boys and 41 girls) and 21 parents participated. Participant characteristics are detailed in Table 2. Based on utilization data collected by the health plan, 30 teen participants had a preventive visit in the past 12 months; however, during the focus groups, 73% (56 of 77) of teen participants reported a preventive visit in the past 1–2 years.

Topic 1: Views on and experiences with preventive visits

Importance of preventive visits: A focus on physical health as the key element of preventive care. Preventive visits were valued by adolescent participants primarily as a tool to ensure and maintain physical health (Table 3). To many adolescents, this could be largely accomplished through a comprehensive physical examination, which was seen as the central and most important part of the preventive visit. Participants reported that through the physical examination, the clinician could accurately evaluate the teen's physical health. One participant described what should be done in a preventive visit: "...they could check your muscles, to see if they're fine, or your calcium levels, or test your blood or something."

Parents' perceptions of the importance of well-visits were similar to the teens' perspectives in that they also focused on physical health ("they're necessary for their vaccinations, they take blood, check for anemia, check their cholesterol..."). However, parent participants also recognized the importance of visits for screening for risky behaviors ("[preventive visits are important] because we don't know if tomorrow they're going to be taking drugs behind closed doors").

Experiences with preventive visits: Brief doctor–patient time leads to few opportunities for effective doctor–patient communication during visits. Participants provided a description of their most recent preventive visit. Most teens described the physical examination in great detail, but had very little to describe in terms of clinician–adolescent communication or discussion of any particular health-related issues (Table 3). Most reported that they had not had such discussions during their most recent preventive visit. One participant described her experience: "He just checks my weight, my height, and stuff, and asks when your last period was and all that. And then he checks your heart and stuff, writes it down, and then kind of says, 'Okay, you're good.' He gives the opportunity to ask [questions], but he doesn't say, 'Do you have any questions,' he's just kind of, 'Okay, if you want to ask, just do it.' But I don't, because he's old."

Parents' experiences were similar. One mother described a recent well-visit for her daughter: "But they didn't ask her

Table 2
Adolescent and parent participant characteristics

	% (n)
Adolescent participant characteristics (n = 77)	
Gender	
Female	53 (41)
Male	47 (36)
Age	
13–15	48 (37)
16–17	52 (40)
Race/ethnicity	
Non-Latino African American	13 (10)
Non-Latino Asian	10 (7)
Latino	60 (46)
Non-Latino white	18 (14)
Education level*	
Currently enrolled in secondary school	93 (67)
High school graduate/GED	7 (4)
Some college	1 (1)
Household Language	
Spanish	53 (41)
English	47 (36)
Parent participant characteristics (n = 21)	
Gender	
Female	95 (20)
Male	5 (1)
Parent age*	
36–45	58 (11)
46–55	37 (7)
57	5 (1)
Highest level of education completed	
Less than high school completion	43 (9)
High school/GED	20 (4)
Some college	33 (7)
4-year college degree	5 (1)
Marital status*	
Never married	10 (2)
Married	35 (7)
Living with partner	25 (5)
Separated, divorced, or widowed	30 (6)
Household language	
Spanish	48 (10)
English	52 (11)

* Five adolescents did not provide education level; two parents did not provide age, one parent did not provide marital status.

anything private, or like, ‘Do you want me to have your parents step out of the room?’ They didn’t really go into [that].”

Barriers to preventive visits: Adolescents described reasons why teens do not attend preventive visits. These were system, teen, and clinician-level factors, including a lack of transportation, excessive waiting room times, inadequate time spent with the clinician, poor clinician–patient relationship, and lack of perceived confidentiality and privacy (Table 3). Participants also cited a lack of knowledge on the necessity of visits: “maybe teens really feel like they don’t need a regular checkup ‘cause they think their body’s fine.” Parents reported many of these same barriers, focusing on waiting room times and poor clinician–patient relationships.

Topic 2: Ways to increase adolescent access to and utilization of preventive visits

The best way to encourage preventive visits is to provide patients with a good, continuous relationship with a clinician who respects their time and confidentiality (Table 4). One teen explained why a good experience with a preventive visit might encourage a teen to return: “[The best incentive is]...just having a good experience at the checkup before. It won’t be a problem coming back because it’s like something positive.”

Structural changes that improve adolescents’ experience accessing and receiving care can increase the likelihood that teens will return for annual visits (Table 4). These changes included the following: (1) reducing the amount of time spent waiting (“you [should be able to] go in there, your paperwork is ready. All right, he’s ready to see you. Boom, you’re out”), (2) increasing the amount of time with the doctor (“the doctor [should] spend more time with you and talk to you about issues and things”), (3) having the same doctor at each visit (“they could give you a doctor you’ve already had so they can make it more comfortable for you”), and (4) assuring the patient of confidentiality (“[if I were the doctor,] I would be like ‘I’m not going to tell nobody,’ and they’ll keep it between you and them”).

Incentives, though not necessary, may be a successful way to get teens to utilize preventive visits (Table 4). Across all groups, adolescents suggested various incentives including cash (\$5–\$20), movie tickets, and retail-store gift cards. Some participants had other ideas including iTunes gift cards, condoms, and raffle tickets for larger prizes like concerts, iPods, or cell phones.

Parents described several elements of the doctor–patient relationship, including effective communication and provider continuity, as important ways to increase adolescent access to and utilization of preventive care. Parents also reported that small incentives, such as gift cards, would be successful in increasing utilization of well-visits. In addition, they suggested the use of reminder calls or post-cards (“there’s something my dentist does which is to send me a letter...to remind me if you forgot your annual checkup”), extended office hours (“having the flexibility to close a little later... because people work and the children go to school”), and decreased waiting time to get an appointment (“I have to schedule it so far in advance...after three months I forget I made the appointment”) as ways to improve adolescent use of well-visits.

Topic 3: Strategies to encourage teens to discuss important health-related topics during preventive visits

Providing teens with confidential face-to-face discussions with a provider they have a continuous relationship with is the best way to encourage teens to discuss sensitive topics with their providers (Table 5). This was described by one

Table 3

Views on and experiences with preventive care

A. Importance of adolescent preventive care: Focus on physical health as the key element of preventive care

Boys, ages 13–15 years, English

...Like, I think if you go get a checkup from a doctor, that they should really check you up-check, like I don't like my check-ups to last five minutes, and then go home. I'm just really cautious about them checking me really over, 'cause my Mom has cancer.

Girls, ages 16–17 years, Spanish household

Yeah, I agree with what she said... because you might be sick with something, for example leukemia and you don't know about it. So it's better I think if you go every year you might know that you have it so there could be something that could cure it.

Parents, Spanish

I'm always on the ball with them [well-visits] because there's a predisposition to diabetes in my family. So I think that it's necessary to go regularly, because maybe even though she looks fine she might not be very healthy.

B. Experiences with preventive care visit: Brief doctor-patient time leads to few opportunities for effective doctor-patient communication during visits

Girls, ages 13–15 years, Spanish

My mom always goes in with me too. And yeah, they used to check my blood pressure and my shots... Only once when they asked my mom to get out of the room because I had to do a heart checkup, I think. So yeah, I had to get undressed. But I was... it was okay.

Girls, ages 16–17 years, English

I was just going to say like there's a lot of bad communication, and it's just like being interviewed. Just like question after question. Just like, "When was the last time you were here?" "What are you here for?" "Now I'm going to check your blood pressure." [And that's it] unless me or my mom like have a specific question or something specific.

Parents, Spanish

Parent 1: The wait is very long and for what? To only be seen for like 15 minutes like he said and that's it. ... An hour or so while you wait for [the doctor] and the nurse... And, and well, the doctor comes in for five minutes, checks here, checks there.

Parent 2: Yeah, that's true. Same with my kid's doctor. You wait a very long time and then in five, no, I'm lying, maybe ten minutes he checks him out and then that's it.

C. Barriers to preventive care

Transportation

Boys, ages 16–17 years, English

I'd say transportation. I don't have transportation... [I] Have to ask someone, like my sister. But they'd have to go out of their way. My mom works until very late and even if she were to take me, the clinic closes early and she wouldn't be able to take me after work. [The bus....] well, that's what I won't do. It's too far and it takes too long.

Waiting Time

Girls, ages 16–17 years, English

My doctor's horrible with time. I literally waited, my last checkup, was two and a half hours waiting in the room, with a called-in appointment, and then I got in the room, and I waited another hour. And all I got was a shot.

Parents, English

The waiting period is so long. I mean, you have an appointment at nine o'clock and you're sitting there until twelve o'clock.

Time with provider

Girls, ages 16–17 years, Spanish

Yeah, it's like you wait forever. When I go to the doctor I wait I would say for about an hour. And then I go inside into the actual room. I wait there like for 20 minutes. The doctor comes for like three minutes, leaves and that's it. And we're done, yeah.

Boys, ages 16–17 years, English

Sometime when you go to the doctor, like, say around afternoon, and stuff, they're already tired, and when they see you, they're like, "Aah." And they really don't pay attention to you and it seems like they just give you a few minutes and they're out the door.

Dissenting view: boys, ages 16–17 years, English

It's better if you have a quick doctor that you know is going to just get you in and get you out.

Provider-patient relationship

Boys, ages 16–17 years, English

My doctor just makes me feel like business. Like it's in and out and doesn't really spend time with you. It's just business and they may not take time to really talk to you. You're in and out.

Parents, Spanish

...they don't have time for us, no, like our kids don't deserve it... The attention, to give them half an hour, twenty minutes—to examine them like they should.

Parents, Spanish

Yeah, I ask [my teenager why he doesn't want to go to the doctor] and he says, "I don't like that doctor anymore," he says, "Because he's very, I mean he's real rude when you ask him things."

Dissenting view: boys, ages 13–15 years, English

But my doctor, the one I have really makes me feel comfortable, he asks me questions and just is really cool and really, you know, respects what I have to say and doesn't laugh or make me feel, you know, like I don't know anything. When I ask him questions he gives me straight answers.

Privacy/confidentiality

Girls, ages 16–17 years, English

I don't feel like there's so much privacy inside hospitals. So then like if they find out, or if they test me, and I'm pregnant, or if I have an STD or whatever, then like where does my privacy go? They're going to call my parents, they'll totally freak out. I'll get kicked out and stuff like that. And they start flipping. So they become insecure, and they won't tell anyone, so they just like end up becoming runaways, I guess.

Dissenting view: parents, English

Now they have a woman doctor that really listens or she does ask questions, and I mean she'll sit down on their level, "Okay, what's going on with you?" And things he wouldn't tell me he would tell the doctor.

Table 4

Ways to increase adolescent access and utilization of preventive care

A. Adolescents reported that the best way to encourage preventive care use was to provide patients with a good, continuous relationship with a clinician who respected their time and confidentiality.

Boys, ages 13–15 years, English.

...like they don't need to be giving you anything for you to go get a, a checkup for your own health. Like—it's not their health; it's not nobody else but your health, so you shouldn't be getting a reward for letting them check your body for free. Because you know that's already a big reward there, just getting a free checkup and having someone to talk to.

Parents, Spanish

Look, for me the priority is that they're nice. The other stuff that they might give them would be extra, but for me it's understanding, that they attend to us well.

B. Structural changes that improve adolescents' experience accessing and receiving care can increase the likelihood that teens will return for annual visits

(1) Reducing the amount of time they have to wait in the waiting room

Boys, ages 16–17 years, English

And just coming in the doctor's office, and then waiting for like two hours in the waiting room, and then going in, and then waiting for another half an hour, and then the doctor seeing me. And then, she does a checkup and then gives me some medicine, and then like prescribes me some medicine. And then I come out, and then I have to pay 20 bucks. I feel like I'd rather just not go to the doctor at all, you know?

Parents, Spanish

It should be quicker... so that they don't get two hours behind...

(2) Increasing the amount of time patients can spend with the doctor

Boys, ages 13–15 years, English

That if you go get a checkup that the doctor should sit there and really talk about like, like really talk about your checkup and like if you ask him questions to get like, like to be there for you and like answer your questions.

Dissenting view: boys, ages 13–15 years, English

Yeah it did seem like it was only five minutes, but now that I think about it, I wouldn't want it to be any longer than that. I wouldn't want—I wouldn't want to go out of there and be like, oh, I'm so happy that it was so long.

(3) Having the same doctor at each visit

Girls, ages 16–17 years, Spanish

Sometimes it might take time too though, because the doctor... if you barely meet somebody and you're supposed to open up to them, you might not open up that same day. It might take even a few hours if you're that fast into trusting somebody. It might take days or weeks or maybe months.

(4) Assuring the teen of confidentiality

Boys, ages 16–17 years, English

I think if they told us, like straightforward that they wouldn't tell our parents, if we had any personal questions that we don't want our parents to know about. If they told us that they'll keep it confidential, we would feel more confident in telling them and asking them questions."

Boys, ages 13–15 years, English

Or, or is it that, that some teens just want to like, when they go get a checkup, maybe they just want to go by themselves, cause they don't want their parents to know, 'oh, I'm going to get a checkup'. Cause some parents—like my Mom—get mad. My Mom, if I told her, 'I'm going to some medical clinic, you know, get a checkup; 'what you getting a checkup for?' 'What are you doing?' Like they just start judging you like, they start like—...And immediately they get all, You know? 'What's wrong with you? What are you doing?' It's just, like on your back about it, so— They [parents] interrogate more than a policeman.

C. Both teens and parents reported that incentives and gifts, though not necessary, would be a successful way to get teens to utilize preventive visits

Girls, ages 16–17 years, English

Moderator: *Okay, what types of things could be raffled off?*

Adolescent 1: *iPods.*

Adolescent 2: *Cell phone.*

Girls, ages 13–15 years, English

Moderator: *What are some other incentives that they might be able to give out?*

Adolescent: *Concert tickets, raffles, concerts... little gifts here and there.*

Parents, English

Well, like when you have a co-payment, pay them to go. Give them \$5. They'll be more than happy to get down there to the doctor.

Dissenting View: Boys, ages 16–17, Spanish

I got one of those in the mail a month ago. It said you could go to the doctor for a checkup, they'll give you like a \$20 gift card. But I still didn't go. I wanted the \$20—I was just too lazy.... they should offer \$75. I would have gone.

D. Other suggested changes.

Girls, ages 16–17 years, English

[To make it easier for teens to get to the doctor, clinics could] have like a...like you call your clinic [and ask] 'You guys think you could pick me up?' And like the clinic, yeah... the clinic provides transportation. That would be pretty tight, too.

Boys, ages 16–17 years, English

Adolescent 1: *[In the clinic waiting room] They have a lot of magazines, but not a lot of kids our age [like] to read magazines and stuff while we're waiting for something. Especially stuff on like diabetes magazines and that stuff. I would like videos and games to be there or they should have magazines that we like to read.*

Adolescent 2: *Like music videos, stuff like that.*

Adolescent 3: *Video games...like PS Tour or something*

Girls, ages 13–15 years, English

Also because you know how like on BET or MTV they have the AIDS commercial and Alicia Keys comes out and says, 'Oh, go get tested,' and different types of artists come out. So maybe [Health Plan Name] can get some celebrities, 'Oh yeah, I go to [Health Plan Name], this and that. Make sure you guys go get checked out' or whatever and they rap about it or whatever, sing about it. [Health Plan Name] is hosting Chris Rock, this and that. I'd be like oh yes, Chris Rock is going to the clinic.

Table 5

Ways to encourage teens to discuss important health-related topics during well-visits

A. To encourage discussion of sensitive topics with their providers, most teens favored confidential face-to-face discussions with a provider they had a continuous relationship with.

They focused on four elements of the doctor-teen relationship to encourage teens to discuss sensitive topics with providers:

(a) Provider Continuity

Boys, ages 13–15, English

Yeah. Maybe you just want to talk to your doctor about something personal and you don't want your parents to know. But my doctor, the one I have really makes me feel comfortable, he asks me questions and just is really cool and really, you know, respects what I have to say and doesn't laugh or make me feel, you know, like I don't know anything. When I ask him questions he gives me straight answers.

(b) Relationship and Rapport-Building

Girls, ages 16–17, English

I think sharing personal experiences. Like if they have children, say they're sexually active, and share their experiences with their children, and how they opened up to them, and told them. I think that would make it more comfortable.

Boys, ages 13–15, Spanish

Give examples of how they were when they were like us....Yeah. They could say, when I was your age, I was curious about these sorts of things: Are you curious?

(c) Confidentiality

Boys, ages 13–15, English

It's not, it's not a problem that they tell my parents because eventually, I tell my parents everything. But, like, the reason why I tell you is because I'm not ready to tell them yet, but then they just go and tell them anyway, and they just bring up the issue and I think other teens might also have this problem and that's reason, like he said, that they might not ask doctors questions they have because they're worried about parents finding out.

(d) Privacy (time in visit without parent present, provider-initiated)

Girls, ages 16–17, Spanish

The doctor's supposed to ask... have a certain quality time with teens, and for the parents to step out of the room. Just for a conversation, not to check anything. When the doctor's going to check something, then the mother should be in there, but if it's just like a one-on-one conversation and it's personal, I think the mother should leave.

Parents, English.

Well I started thinking afterwards that yeah, because he's a man and I'm a woman. So even if I'm uncomfortable I have to respect my son and realize that even if I want to know everything he talks with his doctor I can't and I have to respect that. And his doctor never tells me what they talk about.

Dissenting view: Boys, ages 13–15, English

By phone. 'Cause I don't like really talking to doctors like face-to-face.

B. Technology-driven tools (including text messages, MySpace, and instant messaging) can also be used to encourage discussion of sensitive topics, and to augment risky health behavior screening and counseling outside of the face-to-face office visit.

Girls, ages 16–17, English

...your doctor's not always there 24/7. And I mean, if you e-mail, you have more likely of a chance of figuring out what's wrong with you, and you don't feel uncomfortable talking to someone you don't know, because you're not talking directly to them, you're talking to someone who has a degree and knows what they're doing, but you don't have the-for-me-insecurity of saying, 'Oh my god, this person's going to judge me.' And also, if your doctor goes on vacation, and you can't see your normal doctor, then it's just really uncomfortable to tell your whole story to someone else in order for them to understand, and then by the time your doctor comes back, you know, you finally figure out what's wrong with you, when you could've just texted or e-mailed or called on the phone.

Girls, ages 13–15, English

MySpace... [what if] there's a link to [Health Plan Name] and perhaps you might have a chat room with a doctor from [Health Plan Name]. And then you can like make a profile if you want to, a [Health Plan Name] profile. That would be so cool.

Girls, ages 13–15, English

Adolescent 1: *I think that would be a good idea, the chat line on the internet for doctors.*

Adolescent 2: *A lot of people do AIM [AOM Instant Messaging] and all that stuff.*

Adolescent 1: *Dr. AIM.*

Girls, ages 16–17, Spanish

Oh yeah, I'd want it to be more private. Yeah because somebody might be able to hack into your MySpace and actually read the messages and stuff.

Parents, English

Yeah, I don't want to have a doctor just texting or e-mailing my son. I want to filter the stuff. I only have until he's 18, and so I'd prefer to filter it.

Parents, Spanish

Parent 1: *Like [Health Plan Name]'s site, for example. A [Health Plan Name] ...website would be good... Then because if I see they'd have a separate web site I'd be more comfortable.*

Parent 2: *There'd be pages on it that said [Health Plan Name]*

Parent 1: *... that open email, but if I see she's talking, that it's a, that the site is from [Health Plan Name] then yes I'd feel more comfortable... And she's reading something that I know will be good for her health...*

participant who wanted a better relationship with his clinician: "They [the patient and doctor] should have like a little relationship, like a little kind of friendship... because I know people who actually talk to their doctors, and tell them everything. I think you've got to have that relationship to feel comfortable."

Four elements of the doctor-teen relationship are critical to encouraging teens to discuss sensitive topics with providers: (a) provider continuity, (b) relationship and rapport-building, (c) confidentiality, and (d) privacy (time in visit without parent present). For provider continuity, teen participants reported that it was easier to talk with

a clinician that they knew and with whom they had a professional relationship (“they don’t even know you and you just may not feel comfortable asking them questions that are more private”). For relationship and rapport-building, participants reported that clinicians should try to make a personal connection with the teen (“I think a doctor should come in and not interview you, but talk to you.... You want someone that will be able to connect with you in a way so that way you’ll feel comfortable...not feel like you’re being investigated for murder or something”). Confidentiality and privacy were also important; many participants asserted that it was the clinician’s responsibility to provide assurances of confidentiality and private time to talk without the parent present (“I think that when they’re talking about stuff like that, as far as HPV, that the doctor should at least let the parent step out”).

Technology-driven tools (including text messages and MySpace) can also be used to encourage discussion of sensitive topics, and to augment risky health behavior screening and counseling outside of the face-to-face office visit (Table 5). These tools were generally viewed as viable options for receiving information and counseling on sensitive health-related topics. For many, these options provided greater convenience and anonymity, and fewer hassles than an in-office visit with the clinician. One participant reported that in using these technology-based tools, some teens “probably feel more comfortable, because maybe some people are shy ... They might feel like face-to-face with their doctor they’ll get intimidated.” Another explained why MySpace would be useful: “I bet if there’s 100 students on MySpace and...a doctor posted a bulletin about information, about at least say 75–80 will probably reply to the message. I guarantee you because a lot of kids which are embarrassed or something and they don’t want to speak on something.” Some teens also wanted additional assurances that their communication would be strictly confidential (e.g., password-protected communications).

Parents described the importance of the clinician–patient relationship (continuity, rapport, communication) in encouraging teens to discuss sensitive topics during well-visits. Although some parents supported the use of the internet as a tool to provide sensitive health information to adolescents, there were many who did not. Many were concerned about lack of parental control over what information their children received through the Internet, and preferred information to be provided in a form they could more easily access (i.e., mailed or in-office brochures). Some described the importance of private child–clinician time during well-visits (“So that she has the confidence, so she doesn’t have that doubt, ‘What if somebody finds out?’”), whereas other parents expressed more ambivalence about “private time” (“In a way I’m comfortable with it, but then I’m not”).

Discussion

Adolescents and their parents reported that the most effective way to encourage preventive care utilization among

adolescents was to directly address the multiple barriers they faced in using care. They reported that this could be accomplished by providing adolescents with timely, private, confidential, and comprehensive preventive visits with a clinician with whom they have a continuous relationship. Additionally, adolescents and parents endorsed several other ways to encourage adolescent utilization of preventive care, including the use of patient incentives. Finally, adolescents cited four elements of the doctor–patient relationship (continuity, rapport, confidentiality, and privacy) as well as various technology-driven tools (internet, text messaging, social networking websites) that could improve the delivery of important sensitive health information to adolescents; not all of these were supported by parents.

Our findings on barriers to adolescent well-visits are supported by findings from previous studies that have examined adolescent-reported barriers to accessing and using general health care services. In a previous study of 10th graders, the major barriers to receipt of health services included anxiety, poor access, and the perception that care was not needed [12]. In another study, 9th graders rated clinicians’ interpersonal skills and confidentiality as highly important to utilization [13,25]. In addition to these provider characteristics, we also found that structural barriers to care (e.g., waiting room times, provider continuity) that apply specifically to clinical settings were important to teens.

Few published studies have examined adolescent perspectives on the use of patient incentives for encouraging adolescents to utilize preventive services. A 1997 systematic review of published data on financial patient incentives found that small incentives may be a cost-effective way to improve patient compliance [26]. Another review of interventions to improve adult preventive care found that the most consistently effective interventions were organizational changes and financial incentives [27]. In the focus groups, adolescents and parents were supportive of incentives and thought that they would be effective in encouraging teens to attend well-visits. The use of patient incentives for adolescent well-visits has not been formally evaluated in the clinical literature; however, they have been used by various health plans with reported success [28].

Researchers have begun to examine the utility of technology-based tools as a way to improve adolescent preventive care [19,20]. Our findings suggest that many of these tools (e.g., social networking websites, text-messaging) would be well-received by adolescents and potentially useful in improving the delivery of preventive services; however, we also found some discrepancy between the views of adolescents and parents on this topic. In a previous study, parents of adolescents reported that health care providers could use information technology to share adolescent health information with parents [29].

There are multiple drawbacks to using technology-based tools as an aid in the delivery of preventive care, including privacy concerns, access issues, and costs. However, to provide adolescents with comprehensive care, we may need

to incorporate these tools frequently utilized by teens. Through the Birds and the Bees Text Line, a service of the Adolescent Pregnancy Prevention Campaign of North Carolina, teens can “anonymously” text in their questions about sex and get an answer (including referrals for more complicated concerns) by cell phone text-message within 24 hours [30].

Child and parent perspectives are an important part of developing strategies to improve both preventive and general health services. These perspectives have been elicited and used for health care services for the general pediatric age range, and for younger children specifically [13,29,31–34], as well as for health service evaluation tools, and development of primary care interventions and systems of care [35–40]. Although our study focused on the perspectives of adolescents, we were able to augment our data with perspectives from parents. The areas of agreement between adolescents and parents included the importance of the doctor–patient relationship, use of incentives, and structural changes to care. Adolescents placed much more emphasis on confidentiality and privacy as critical ways to encourage utilization of care, and on the use of technology-based tools for the discussion of sensitive health-related topics.

This study has limitations that should be considered when interpreting our findings. Because we were mainly interested in the perspectives of adolescents, we focused our resources on 8 adolescent focus groups, and only conducted 2 parent groups. However, we believe that the small number of parent focus groups serves to enrich our findings from adolescents. Next, our sample was limited to enrollees in one health plan with Managed Care Medicaid enrollees in one geographical area; it is possible that their perspectives may be very different from a sample of enrollees from different plans in other areas. Moreover, a large proportion of the sample either could not be contacted or refused to participate, reducing our ability to generalize findings. Finally, we focused on a limited number of strategies to improve preventive care utilization among adolescents; there are others (e.g., school-based clinics), which were not covered in detail in the focus groups because of an effort to limit the length of the focus group discussions.

Despite its limitations, our study provides important information that can be used by researchers, health plans, clinics, health care professionals, and state Medicaid agencies to increase preventive care utilization among adolescent Medicaid beneficiaries. Health care delivery organizations can assure patients of confidentiality and privacy by implementing protocols for office staff to describe patient confidentiality and privacy procedures to parents and adolescents before the visit, including visit time without the parent. Researchers should investigate the effectiveness of technology-based tools to provide preventive services (and not just for screening or reminders) and investigate the use of patient incentives to encourage utilization. Current reimbursement systems and clinician incentives for preventive care may not support many of the improvements that adolescents say would encourage them to attend preventive visits

(e.g., more time with the provider); alternative reimbursement strategies should be investigated to fully support adolescent preventive care utilization. Finally, our findings suggest that attention to basic quality issues (timeliness, continuity, confidentiality, patient-centeredness) may be one of the most important ways to improve preventive care utilization for this population of adolescents; providing all adolescents preventive care within a medical home is one way to reach this important goal.

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Supplementary data

Supplementary data associated with this article can be found, in the online version, at doi:10.1016/j.jadohealth.2010.01.005.

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Discussion Questions:

1. Was it appropriate that the patient be evaluated and treated without parental consent?
2. Using the ABC Framework for Ethical Issues, evaluate this case and recommend an appropriate course of action.
 - A. Assessment: What additional information do you need to adequately assess the case scenario? Discuss the significance of various pieces of additional information, and how this would affect your perspective.
 - B. Bioethical Principles and Values: What bioethical principles and values are applicable to this case?
 - C. Capacity: Does this patient have appropriate decisional capacity? If not, who is patient's surrogate?
 - D. Decision: What courses of action should be considered? What course of action do you recommend?
 - E. Evaluation: How would you assess the outcome of the decision?
3. Under what conditions can adolescents seek medical care without parental permission?
4. What is an emancipated minor?
5. What is a mature minor?
6. Are there circumstances in which an adolescent patient's confidentiality should be breached?

SEPTEMBER 18

Patient Autonomy: Perspectives in the Humanities (C. Marco, MD)

“The Sea Inside”

“The Diving Bell and the Butterfly”

Objectives:

1. Describe the significance of patient autonomy in medical decision making.
2. Identify factors that may contribute to patient autonomy.
3. Construct a balanced approach to paternalism and patient autonomy.

Recommended Reading:

“The Diving Bell and the Butterfly” (Jean Dominique Bauby)

(130 pages, available on reserve in the Mulford Library or retail from amazon.com or other bookstores).

This book is a quick read, with lots of insight into patient autonomy, and the patient's perspective as a physically disabled patient with intact mental faculties. Highly recommended!

“Informed Consent”, in: Lo, Bernard: Resolving Ethical Dilemmas, A Guide for Clinicians, pp. 18-30.

Bonus Assignment - Due September 25, 2012 before 5:00pm (1point):

Read “The Diving Bell and the Butterfly” and view the movie “The Sea Inside”.

Compare and contrast the perspectives of the patients in “The Sea Inside” and “The Diving Bell and the Butterfly”.

Explain how a physician should incorporate patient perspectives, even if extreme, into the ethical practice of medicine.

Suggested length is 1-2 pages to be submitted via Blackboard Bonus Assignment drop box.

For questions contact Nick Bell.

SEPTEMBER 19

Organ Donation (Dr. Michael Rees) **PLENARY & SMALL GROUP DISCUSSION**

Objectives:

1. Identify ethical issues related to organ donation and transplantation.
2. Describe the significance of altruism in organ donation.
3. List factors considered in identifying organ transplantation recipients.
4. Discuss the application of ethical principles and values to proposals to increase rates of organ donation.

Required Readings:

“Ethical Issues in Organ Transplantation”, in: Lo, Bernard: *Resolving Ethical Dilemmas, A Guide for Clinicians*, pp. 301-310.

“USA confronts looming organ-shortage crisis” (Zwillich T: *The Lancet* 2006; 368:567-8)

“Consent for Organ Donation – Balancing Conflicting Ethical Obligations”, *New England Journal of Medicine* 2008; 358:1209.

Recommended Readings:

“Domino paired kidney donation: a strategy to make best use of live non-directed donation” (Montgomery RA et al: *The Lancet* 2006; 368:419-21)

Assignment:

(No assignment)

Case

Patient A: A 33-year-old Hispanic woman has renal failure resulting from hypertension and has required hemodialysis for 3 years. She is a lawyer and has 2 children. She has maintained a part-time employment schedule and lives at home with her family. She has a traditional health insurance plan that would cover renal transplantation. She has been on the renal transplant list for 2 years.

Patient B: A 58-year-old Caucasian man has renal failure resulting from heroin use and has required hemodialysis for 8 years, and has been on the transplant list for 6 years. He did not complete high school, is unemployed, and is on welfare. He has no medical insurance. He has been drug free on multiple tests for the past 8 years. He has developed a clinically significant pericardial effusion as a result of the renal failure that has required multiple admissions, procedures, and medications.

USA confronts looming organ-shortage crisis

Long waiting lists for organs mean the average time to transplant for some groups is now longer than median survival. Some campaigners see the legalisation of cash payments for donations as the solution to this crisis. Others are proposing a redefinition of "dead". Todd Zwillich reports.

An alarming shortage of transplantable organs in the USA has some ethicists and policymakers demanding new and in some cases drastic tactics for boosting donations.

Confronted by record waiting lists for organs, some are declaring America's system of altruistic donations a failure. They are calling for a reversal of laws banning cash payments for donations and, in some cases, even advocating for changes to who qualifies as dead and therefore able to donate vital organs.

More than 92 400 Americans are currently in line to receive a graft—mostly kidneys—yet less than 14 500 individuals donated last year. The cost in lives and dollars mounts, as billions in taxes are spent on dialysis while would-be recipients often wait 5 years or more for a match. An ever-increasing number are dying for lack of willing donors.

Already average wait times for kidneys outlast median survival for patients with type O or B blood. But as grim as the current situation is, it is the future which worries experts more. Statistics now suggest America's increasing diabetes rate and ageing population could double demand for kidney donations in the next 10 years. Improved surgical techniques will increase demand for other organs too.

Though they are touted as a sign of success by organ procurement authorities, modest increases in living and deceased donations over the past few years cannot come anywhere close to keeping up with demand.

Earlier this summer, the Institute of Medicine (IOM) called for new cardio-pulmonary resuscitation standards that could increase the number of organs salvaged from people who die suddenly outside hospital

from trauma or cardiac arrest. The effort could provide access to some 22 000 individuals declared dead by "circulatory standards", the institute concluded.

"Those really represent an untapped resource", says James Childress, a University of Virginia professor of ethics and chair of the IOM committee that issued the report.

But the IOM generated more controversy for what it did not recommend than for what it did. Its report steered clear of several more controversial moves many observers say are needed to boost organ supplies.

Childress acknowledged in that overall the recommendations were "conservative" in that they broke little new ground. But the report opened up Childress's panel to criticism from commentators who accuse it of tinkering around the edges of a serious shortage in donated organs.

Robert Veatch, a professor of medical ethics at Georgetown University in Washington, DC, is among those

calling on the USA to abandon many of the rules now governing organ procurement. He has gone so far as to recommend altering the legal definition of death so that more donors qualify.

Current law requires "whole brain" death before organs can be obtained from a donor. But Veatch advocates moving to a "higher-brain" definition that could classify patients in permanent vegetative states or unconscious comas as legally dead.

The idea is bound to meet with staunch opposition, especially in a country which less than 2 years ago found itself in a political uproar over the fate of a single patient, Terri Schiavo, who was in a persistent vegetative state. But Veatch has urged a series of other moves to increase organ supplies, and he is not alone.

Thousands of patients could be cut from waiting lists if intravenous drug users, men who have sex with men, and other high-risk people were permitted to donate, Veatch argues.

We do not have the rights to reproduce this image on the web.

Long waiting lists for organs mean individuals with some blood types die before transplants can be done

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US campaigners claim paying for organs could prevent "organ-tourism" operations

Their organs could be reserved for terminal patients for whom the risk of infection pales in comparison to the threat of imminent organ failure.

He also backs a new system of donation incentives now considered anathema in an American procurement system built on pure altruism. They include points that let committed donors or their loved ones gain priority positions should they find themselves on an organ waiting list.

Veatch also counts himself a recent convert to a vocal group advocating for a repeal of the federal ban on inducements for organs so that people can be paid for their organs.

"Historically, I resisted all market mechanisms because of the risk of injustice. I think we've waited long enough. There are too many people dying. I think it's time to begin limited experiments with cash payments", Veatch recently told the President's Council on Bioethics.

The view is shared by a group of libertarians and free-market conservatives who have recently taken to America's editorial pages in defence of a regulated market in human organs.

Sally Satel, a psychiatrist and resident scholar at the American Enterprise Institute, a free-market think-tank, is one of the group's most vocal backers. In an interview, Satel said that she gave organ donation issues no thought before her own kidney failure resulted in a successful transplant in March.

Satel called the IOM "timid" for recommending against even experimenting with financial incentives. She says that though payments for organs may be distasteful, it is a better option than the alternatives of shortages, black-market transactions, and international "organ tourism".

She even backs moving to a system of "presumed consent" that assumes everyone is a donor who does not proactively opt out.

"The verdict is in: relying solely on altruism is not enough", Satel wrote in the *New York Times* recently. "It sounds radical", she told *The Lancet*. "But this is a crisis situation."

Still, the IOM was far from alone in its opposition to cash payments for organs. In an at-times testy exchange before the President's Council, president of the United Network for Organ Sharing (UNOS) Francis Delmonico pledged that his organisation would vehemently fight any move to enshrine an organ market into law. It is backed by other weighty groups, including the National Kidney Foundation and the American Society of Transplant Surgeons.

"That [waiting] list is growing because of inadequate medical care and it's not just solvable by buying organs", Delmonico said.

The risk of injustice is mainly what has held back cash-for-organs schemes in the past. Opponents have long warned that cash incentives would disproportionately attract the poor and provide a perverse incentive amounting to exploitation. After all, who is more likely to donate for cash: \$200 000 a-year lawyer, or a \$10 an-hour labourer?

"We simply cannot ignore the fact that the sellers are going to be the poor, predominantly. Most well-off people are not going to sell their organs as a way to buy a third car. The people who are going to sell their organs are going to do it largely, I think, as a kind of act of desperation", says Eric Cohen, director of bioethics at the Ethics and Public Policy Center, a conservative Washington think-tank.

Advocates insist they are not calling for a free market in organs, but rather a regulated one where prices are set and transactions are monitored. Surgeons and patients who object would be able to opt out, and prospective donors would be given in-depth information about their choices and rights under the system, they say.

The goal, says Richard Epstein, director of the law and economics programme at the University of Chicago Law School, and a vocal critic of UNOS, is to reverse the current system where a ban on payment snuffs out any incentive to donate.

"Do not get yourselves into the illusion that there is something so unique and distinctive about the questions of organs or body parts or any form of transplantation that the general rules of economics do not apply", he says.

The pressure of the shortage is showing. Websites such as matchingdonors.com now allow individuals to make direct pleas for organs and pair them with willing donors, causing some advocates to complain of an unfair disadvantage for poor patients with no access to computers. It is not unheard of for desperate patients with the means to use roadside billboards for their appeals.

The federal government is heading up an initiative to maximise organ procurement at medical institutions and increase public awareness of donation. Meanwhile, the President's council is deliberating on its own set of recommendations.

Daniel Foster is an internist at the University of Texas Southwestern Medical Center in Dallas and a member of the President's Council. He warned that kidney failure patients in the city now wait an average of 5 years before finding a donor. "I think we've got to do something radical about it", he says.

Todd Zwillich



Original Article

MARCH 20, 2008

Consent for Organ Donation — Balancing Conflicting Ethical Obligations

Robert D. Truog, M.D.

Organ transplantation is truly one of the miracles of modern medicine, saving the lives of many patients and improving the quality of life for many more. Given the ever-increasing gap between

the number of organs needed and the supply, clinicians have an ethical obligation to help ensure that the desires of people who want to donate organs are respected. The Department of Health and Human Services took up this challenge in 2003, when it collaborated with leading transplantation organizations to launch the Breakthrough Collaborative, calling on all hospitals to increase their organ-donation rates to 75% or higher.

In addition to facilitating patients' exercising their right to donate organs, however, clinicians have an obligation to ensure that the consent process is informed and voluntary. During the past few years, changes in

the laws, regulations, and guidelines surrounding the procurement of organs for transplantation have created tensions between these two ethical commitments. As one physician recently told the *Washington Post*, "If you promote organ donation too much, people lose sight that it's a dying patient there. It's not just a source of organs. It's a person."¹

A few examples illustrate the evolution of this tension. In 2006, the Commissioners on Uniform State Laws worked with the transplantation community to amend the Uniform Anatomical Gift Act (UAGA). As originally amended, the act stipulated that physicians must continue the use of life-sustaining treatments for

dying patients until the local organ-procurement organization (OPO) could determine whether the patient's organs were suitable for transplantation, even if the patient had an advance directive in place stating that such treatment was not wanted. When critical care physicians became aware that they could be required to administer life-sustaining treatments against the expressed will of their patients, they voiced their ethical concerns to the commissioners, and in 2007, the UAGA was again amended to emphasize that the attending physician should consult with the patient or surrogate as early as possible to determine and follow the patient's wishes, even if doing so resulted in the loss of potentially transplantable organs.²

Although this particular issue seems to have been resolved, further tensions remain. One is the way in which regulations from

the Centers for Medicare and Medicaid Services are being interpreted and implemented. These require hospitals to notify the local OPO "of individuals whose death is imminent or who have died in the hospital" and to ensure that the person who initiates the request to the family is a representative of the OPO or a "designated requestor." Although it is theoretically possible for hospital clinicians to be trained as designated requestors, in practice this person is almost always an OPO representative.

These representatives therefore have responsibility for obtaining informed consent for organ donation. An ethically valid informed-consent process should consist of a balanced discussion of the available options and counseling to help patients or their families reach the choice that is best for them, including the provision of information about the urgent need for organs and the consolation that many families derive from knowing that their loved one was able to help others. Recently, however, OPOs adopted a strategy known as the "presumptive approach for organ do-

nation."³ Under this approach, organ-procurement coordinators are encouraged to introduce themselves to families as members of the "medical team" or as "grief counselors," without necessarily disclosing that their role is explicitly one of dual advocacy, since — operating under the assumption that organ donation is simply "the right thing to do" — they simultaneously represent the interests of the patient or potential donor and the pool of potential recipients. The table contrasts typical phrases used in the standard approach with those endorsed by OPOs using the presumptive approach, some of which are clearly misleading or even manipulative. These concerns are not just theoretical. As a critical care physician in Chicago observed, "I have seen these guys come in and almost browbeat families into submission to get them to donate organs."¹

The presumptive approach clearly undermines many of the core elements of informed consent. An instructive contrast can be drawn between approaches to obtaining consent for participation in medical research, on the one hand, and for organ dona-

tion, on the other. The two activities have much in common: both participation in research and organ donation are altruistic gifts offered primarily for the benefit of others, both may involve some risk or harm to the patient or family, and in both cases, clinicians have an obligation to support the desires of patients. Yet in seeking informed consent for research, we have adopted meticulous safeguards to ensure that the consent is fully informed, voluntary, and free of any manipulation or coercion, whereas in the case of organ donation, we require that families be counseled by people whose agenda and approach are inherently conflicted. This strategy seriously threatens our commitment to the importance of informed consent and undermines fundamental principles that support respect for patients and their families. Although OPO representatives possess a wealth of information that families could find useful in decision making, they should be as committed to an impartial and transparent process as those who seek consent for research.

The presumptive approach is

Key Elements of the Standard Approach and the Presumptive Approach to Counseling Potential Organ Donors.*

The Standard Approach	The Presumptive Approach
"This is Mary. She works with families like yours who have lost a loved one. Would it be possible for her to speak with you for a moment?"	"Mary is a member of our team. . . . She is going to speak with you and answer any questions you might have."
"I'm here to provide you with information about organ donation."	"I'm here to provide you the opportunity to donate your loved one's organs."
"Some families choose the option of donating their loved one's organs. I am here to help you make the decision that is best for you and your family."	"You and your husband now have the opportunity to make your son a hero through the gift of organ donation."
"We will support whatever choice you make."	"Most people, if given the chance to save a life, will do it."
"If you decide to donate. . . ."	"When you decide to donate. . . ."
"Would you like me to give you some time before you make your final decision?"	"If you do not have any more questions, I will now guide you through this process."

* Quotations are from Zink and Wertlieb.³

of particular concern in light of the reaffirmation in the amended UAGA of the importance of acting on the first-person consent of patients, as expressed through organ-donor registries, regardless of the wishes of the patient's family.² On first impression, this makes good sense: families should not be able to veto the wishes of patients. But some have voiced concern that a patient's general indication of a willingness to donate (e.g., a checked box on a driver's license) could be interpreted as indicating a desire to donate through newer procedures that were not envisioned by the patient at the time the intent was expressed. For example, as of July 2007, all transplantation hospitals are required by the United Network for Organ Sharing to develop and follow protocols that facilitate organ donation after cardiac death.⁴ Unlike organ donation after brain death, in which patients are declared dead before organ-procurement procedures begin, some protocols for donation after cardiac death involve the exposure of dying patients to resuscitation efforts, placement of central venous catheters, the administration of heparin and vasodilators, and withdrawal of life support under

sterile conditions in the operating room. Although consent from the next of kin is required for any antemortem procedures, under the presumptive approach, families may feel pressured to give consent by OPO representatives who choose to assume that the patient's general willingness to be an organ donor indicates a willingness to undergo these additional procedures before death, which may not be the case. As one ethicist has noted, "Most people who agree to be organ donors think about it in terms of what will happen to their body after they die. This [approach] has implications for what they do to you before you die."⁵

Both clinicians and OPOs therefore face conflicting ethical obligations. The growing transplant waiting lists obligate us to strive to increase the supply of transplantable organs. But our commitments to respecting the rights of our patients and their families require that consent be obtained by people who are, in turn, committed to being fully transparent, fair, and evenhanded. When we are faced with competing ethical obligations, our challenge is to find a balance that will preserve our most essential ethical principles. Over the past

few years, the pendulum has swung too far in the direction of procuring organs at the expense of commitments that are fundamental to the patient-physician relationship. If uncorrected, this trend could substantially erode the public's trust in the transplantation enterprise, to the ultimate detriment of people who desire to make these remarkable gifts as well as those who are desperately in need of them.

A letter to the editor from Luskin and colleagues at the New England Organ Bank appears on page 1297.

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Taking Your Child's Breath Away — The Extension of Asthma's Global Reach

Eva C. Mantzouranis, M.D.

On a clear summer day, as Michael runs through the fields playing with his friends, the view from his farm is spectacular. You can look past the hills where his family grows olives and raises sheep to the

Mediterranean Sea. Last winter, however, the picture was far less tranquil for the 4-year-old and his family. In their small cottage that is heated by burning olive pits left over from the olive-oil press, with his mother cook-

ing over an open fire and his father smoking two to three packs of cigarettes a day, Michael developed frequent colds, a chronic cough that worsened considerably at night, and shortness of breath when he played.

Domino paired kidney donation: a strategy to make best use of live non-directed donation

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Current models for allocation of kidneys from living non-directed donors

Living non-directed (LND) donors, also known as altruistic, good Samaritan, anonymous, or benevolent community donors, are a new and rapidly growing source of solid organs for transplantation.¹⁻⁶ The willingness of individuals to donate organs without a designated recipient has been unexpected, but has probably developed as a societal response to the growing crisis in organ availability. In the context of this shortage, health professionals have attempted to make the best use of kidneys from LND donors. We present a novel application of paired donation that has the potential to multiply the number of recipients who can benefit from each LND donation.

At present, there is no universally accepted system for allocation of organs from LND donors. Selection of recipients has been at the discretion of the transplant centres where LND donors have presented and has generally been guided by one of three models: donor-centric, recipient-centric, or sociocentric allocation.⁷ Each of these models is supported by valid ethical arguments.²⁻¹²

The main goal of donor-centric allocation is to ensure a successful outcome for the recipient. A good outcome provides justification for medical professionals to assist a person who is not ill to put themselves in harm's way to aid another. A positive result also gives an LND donor a sense that their effort was fruitful and worthwhile. However, this model dictates allocation to the healthiest patient on the transplant waiting list. These recipients are the most likely to have good outcomes on dialysis or with organs from deceased donors, and therefore are arguably the least in need.

Recipient-centric allocation is based on the belief that society has a responsibility to protect its most vulnerable and disadvantaged members. Under this model, organs from LND donors are given to those patients in the greatest need, those for whom a kidney transplant might be truly life saving, or those disadvantaged under the existing system for allocation of kidneys from deceased donors. This model mainly benefits children, patients who have no vascular access, highly sensitised patients, and those with life-threatening medical illnesses related to dialysis. However, because the recipient-centric model accords priority to such patients, it tends to yield unacceptably poor transplant outcomes, and could lead to a negative public perception of LND donation.

Under the third model, of sociocentric allocation, the LND donated organ is treated as a public resource that

should be allocated in the fairest and most equitable way, irrespective of outcome or need. This rationale dictates that the recipient should be the patient at the top of the transplant waiting list administered by the United Network of Organ Sharing (UNOS). UNOS oversees the allocation of deceased donor organs in the USA, using a so-called match run algorithm that ranks potential recipients according to agreed criteria. The limitations of this model are that a patient at the top of the list will probably receive a kidney from a deceased donor in the near future, and that they will have already incurred the costs, and exposure to comorbidity, that result from a long period on dialysis.

The waiting list for deceased donor kidneys can be circumvented by patients who find a willing live donor. But direct donation might be complicated by differences in blood type and by HLA sensitivity. Some incompatible donor-recipient pairs enter into programmes that facilitate paired donation, also known as kidney paired donation. A donor and recipient who have incompatible blood groups or HLA sensitivity can be matched with another incompatible pair, to result in two compatible transplants (figure).¹³⁻¹⁹ Although there are many ways to match up a pool of incompatible pairs, the mathematical technique of optimisation helps to find out which matches will yield the best results.¹⁴ Nevertheless, even in paired-donation programmes in which mathematical optimisation is applied, more than 50% of the incompatible pairs in the pool remain unmatched.^{19,20} In many cases, pools of incompatible donor-recipient pairs have a high proportion of patients with blood types that are hard to match and those with HLA sensitisation.

Domino paired donation

In this study, we examine the effect of allocating a LND donor organ to a pool of incompatible donor-patient pairs. This strategy allows a new type of paired donation, which we call domino paired donation, in which the LND donor's gift initiates a chain of matches. First, the LND donor's kidney is matched to a recipient who has a willing but incompatible donor (figure and panel). The recipient's incompatible donor can, in turn, agree to give a kidney to the next compatible patient on the transplant waiting list, producing a domino effect. In this way, two live donor kidney transplants result, and the LND donor's gift is multiplied.

We have also developed a mathematical simulation to quantify the potential benefit of allocation of LND donors' kidneys by use of the domino paired donation model. Since the first LND donation was reported to UNOS in

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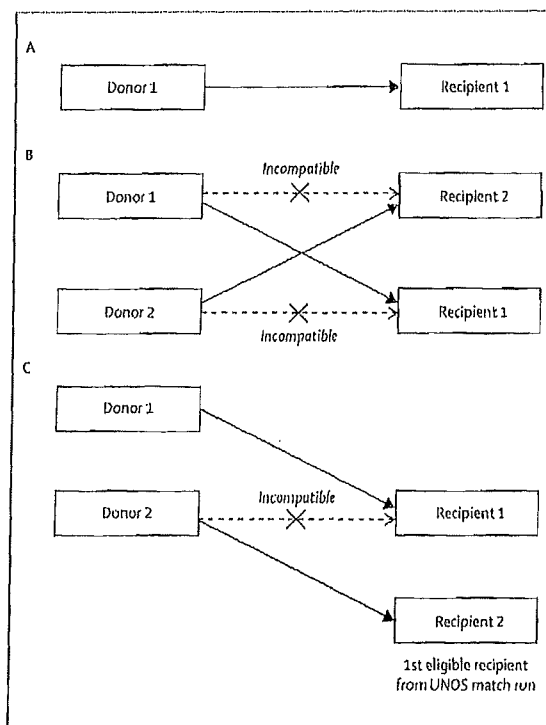


Figure: Strategies to expand the use of kidneys from live donors (A) Current one-to-one model. (B) Conventional paired donation between two incompatible donor-recipient pairs. (C) Proposed model of domino paired donation

1998, this type of kidney transplant has steadily risen in frequency, with a total of 302 procedures reported in the USA to date.¹ We used the optimised algorithm we have previously reported¹⁰ to simulate paired donation by finding reciprocal matches within pools of incompatible donor-recipient pairs. We then compared the results with the numbers of simulated transplants obtained if LND donors were introduced to these pools by use of domino paired donation. On the basis of these comparisons, we estimate that if domino paired donation had been adopted in the USA since the first LND donation, 583 transplants would have been accomplished, rather than 302. The number is slightly less than two transplants per LND donation because not every LND donor will find a match in a pool of incompatible pairs. (Where a domino paired donation cannot be arranged for a LND donor, they can be paired with the next compatible patient on the transplant waiting list by use of a UNOS match run.) Three-way domino paired donation is also possible, and can further increase the benefit derived from each LND donor.

The ethics of domino paired donation

The domino paired donation model would satisfy the ethical tenets of the three main philosophies that are commonly used to guide allocation, and for this reason it could be predicted to gain wide acceptance. The donor-

Panel: A clinical example of domino paired donation

We obtained approval for our protocol from the Johns Hopkins University Ethics Committee and Legal Office.¹⁴ Among the ethical arguments for domino paired donation, the Ethics Committee considered the human consequences of the present shortage of donors and the autonomy of the informed individual to make decisions about their wellbeing to be particularly compelling justifications. Each participant was medically cleared and gave informed consent after counselling about untoward events that might prevent the completion or success of a transplant. All operations were done simultaneously, and anonymity was maintained throughout.

We trialled a domino paired donation in which a 28-year-old LND donor (D1), who had blood type O, gave her kidney to a 48-year-old recipient (R1) with end-stage renal disease from IgA nephropathy. He was in the paired donation pool because he and his 51-year-old wife, D2, had incompatible blood types. R1 was blood type B with strong antibody reactivity to the A blood-group antigen, and his wife (D2) was blood group A1. D2 agreed to donate to a patient on the transplant waiting list. According to standard procedure, a UNOS match run was done for blood type A. The first eligible patient on the transplant waiting list was a 48-year-old woman (R2) with renal failure from polycystic kidney disease. R2 had been waiting on the list for a kidney from a deceased donor for 2 years. Domino paired donation took place as shown in figure 1: R2 received a kidney from D2 at the same time that R1 received a kidney from the LND donor (D1). Both recipients were shown to have serum creatinine concentrations of 124 µmol/L. The reference range for serum creatinine is 45–140 µmol/L.

centric model would be served because donor paired donation would increase the likelihood of a good outcome, by spreading the risk of recipient graft loss across more people. That is, even if the transplant of the LND donor's kidney was unsuccessful, domino paired donation would enable a second chance of a positive result, when the paired donor's kidney was given to a recipient on the waiting list. According to the recipient-centric model, priority should go to recipients with the greatest need or disadvantage. In many cases, incompatible donor-recipient pools have a high proportion of patients with blood types that are hard to match, and those with HLA sensitisation. Therefore, the domino paired donation model would help these patients, who are disadvantaged by the current allocation system because they tend to wait longer for a kidney and are more likely to develop the comorbid disorders associated with prolonged dialysis. The sociocentric allocation model aims to achieve fairness and equity by allocating kidneys to patients at the top of the waiting list. The domino paired donation model would conform to this standard, since the paired donor's kidney would be

allocated to the next compatible patient on the UNOS registry.

Conclusion

At a time of growing crisis in organ availability, this study shows that the current system of allocating LND donor organs does not achieve the greatest possible benefit from this new and growing source of kidneys. Implementation of domino paired donation on a national or regional scale should improve consistency and fairness across transplant centres, but would reduce each transplant centre's autonomy in making decisions about allocation of organs. Domino paired donation would also be affected by the same practical limitations as paired donation in terms of the logistical difficulty of arranging paired donations between diverse and distant institutions. Although in our limited experience LND donors have welcomed this allocation model, we would need to better understand the attitudes of LND donors, paired donors, and the public before domino paired donation is adopted as a standard policy. However, our study shows that the use of domino paired donation has the potential to increase both the quantitative and qualitative benefit of each LND donation.

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Conflict of interest statement

We declare that we have no conflict of interest.

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Case Discussion Questions:

1. If a single kidney were available for transplantation, and you were the organ procurement agent making the decision, which patient would you recommend to receive the transplant? Why?
2. We often refrain from making value judgments on patient lifestyle, insurance status, or other factors in the practice of medicine. Yet often these factors determine transplantation eligibility. Is this ethical? Why or why not?
3. Using the “ABC Framework for Ethical Issues”, how would you approach this case?
 - A. Assessment: What additional information do you need to adequately assess the case scenario? Discuss the significance of various pieces of additional information, and how this would affect your perspective.
 - B. Bioethical Principles and Values: What bioethical principles and values are applicable to this case?
 - C. Capacity: Does this patient have appropriate decisional capacity? If not, who is patient’s surrogate?
 - D. Decision: What courses of action should be considered? What course of action do you recommend?
 - E. Evaluation: How would you assess the outcome of the decision?
4. What strategies should society entertain to increase organ donation?